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Predictors of Quality of Life in Lupus Patients: A Study of Coping, Cognitive Distortions, and Social Support

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PREDICTORS OF QUALITY OF LIFE IN LUPUS PATIENTS: A STUDY OF COPING, COGNITIVE DISTORTIONS, AND SOCIAL SUPPORT

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Dedication and Acknowledgements

This dissertation is dedicated to the memory of my mother, Virginia "Betty" Osbourne. You were the inspiration for this study. I miss and love you very much with every passing day. This study is also dedicated to any individual who has been diagnosed with lupus—all of whom have been affected by this disease in their own way. Keep fighting, my Lupus Warriors!

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Abstract

The purpose of this study was to determine whether cognitive distortions, social support, and/or levels of coping skills predict quality of life (QOL) for women with SLE. The total sample consisted of 62 women ranging in age from 18 to 55 years. This study was conducted online via SurveyMonkey in an effort to reach the specialized SLE female population and recruit individuals who otherwise may not have been able to participate due to limitations in mobility and/or lack of transportation. The measures consisted of the Inventory of Cognitive Distortions (ICD), the WHOQOL-BREF (WHOQOL), the Multidimensional Scale of Perceived Social Support (MSPSS), and the Brief COPE. Results revealed that 49.5% of the variability in scores on WHOQOL-BREF were attributable to differences in scores on the ICD. A test of the individual predictors revealed that only social support and coping made significant contributions to the prediction of the QOL. In other words, the linear combination of social support and coping is useful in predicting QOL. Additionally, findings demonstrated that high levels of distorted thinking were highly correlated with lower QOL.

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Chapter 1: Introduction

Statement of the Problem

Approximately 5 million people throughout the United States have a form of systemic lupus erythematosus (SLE; D'Cruz, Khamashta, & Hughes, 2007). SLE is a relapsing-remitting condition in which periods of mild disease activity alternate with flares of increased disease activity. SLE is mainly manifested in women, but also found in children and men, with clinical and pathologic manifestations involving almost all bodily organs (Lau & Mak, 2009). Symptoms can include fatigue, joint pain and sensitivity, malar rash on the face, and skin photosensitivity (D'Cruz et al., 2007). Complications can include kidney damage including kidney failure, cognitive and memory impairment, neuropsychiatric symptoms, blood disorders, and cardiovascular disease (Seshan & Jennette, 2009).

Chronic diseases such as SLE are the leading causes of suffering, disability, and death in the United States (Hanly et al., 2007). Specifically, SLE affects not only patients' physical health, but also their social, emotional, mental, and financial well-being. More than 16,000 new cases of lupus are reported annually across the country; however, that number may be higher due to the lack large-scale studies regarding this pervasive disease. Additionally, the reported prevalence of SLE in the population is 20 to 150 cases per 100,000 (D'Cruz et al., 2007). Although anyone can acquire SLE, about 9 out of 10 adults with lupus are women ages 15 to 45. African American women are three times more likely to get lupus than Caucasian women. SLE is also common in Latina, Asian, and Native American women (Skamra & Ramsey-Goldman, 2010). Further, men are at a higher risk before puberty and after age 50. Despite an increase in lupus in men

in these age groups, two thirds of the people who have lupus before puberty and after age 50 are women (Pons-Estel, Alarcon, Scofield, Reinlib, & Cooper, 2010). African American Latins tend to get SLE at a younger age and have more severe symptoms, including kidney problems, seizures, strokes, and dangerous swelling of the heart muscle (Uramoto et al., 1999).

Persons with SLE may experience a wide range of psychological and social problems that are not always fully captured by descriptions of the disease's physiological consequences alone (Strand et al., 2003). Symptoms may include difficulty concentrating, sleeping, prolonged grief, excessive fear, anxiety, and depression (Strand et al., 2003). Many individuals with SLE also struggle with learning how to accept having the illness (Waterloo, Omdal, Husby, & Mellgren, 1998). Low self-esteem and feelings of guilt are common among individuals with SLE (Waterloo et al.,1998), leading to depression in 30% to 40% of patients (Karlson et al., 2004).

It is not surprising, then, that perceived quality of life (QOL) also suffers. Factors contributing to low perceived QOL include both physical and psychological difficulties. Physically, one must adapt to life with new limitations in energy level and joint pain. Additionally, potential medical complications commonly require tetracycline antibiotics, which can impact an individual's sensitivity to sunlight may also occasionally cause "phototoxic" reactions. These will lead to easy sun burning that will require extra protection against sunlight (Kim & Chong, 2013). Psychologically, the person may grieve the loss of his or her personal identity and cherished goals, which heightens vulnerability to depression, anxiety, substance abuse and suicidality (Kennedy, 2012).

Economically, studies have shown that SLE is associated with substantial burden, in terms of health care resource utilization, as well as losses of productivity due to work capacity impairment (Carls et al., 2009). Direct medical costs, indirect costs due to absenteeism, and indirect costs due to short-term disability in patients with SLE were estimated at $21,499, $3,824, and $2,474, respectively, compared with $8,008, $4,430, and $1,169, respectively, in persons without SLE (Zhu, Tam, V. W. Lee, K. K. Lee, & E. K. Li, 2009a). Generally, costs for inpatient care represent the largest proportion of direct costs.

SLE has an impact on a patient's QOL and ability to work (Krishnan, 2006). Campbell, Cooper, and Gilkson (2008) analyzed the impact of SLE on employment, specifically work status and predictors of job loss, between 2007 and 2008. A follow-up study found that 26% of patients with SLE who were working the year before the diagnosis or corresponding reference year had stopped working at follow-up (Campbell, Cooper, & Gilkson, 2009). Ninety-two percent of patients had stopped working due to their health statuses. Furthermore, 28% of patients were unable to work for a period of two or more months (Campbell et al., 2009). In sum, SLE impacts QOL in SLE patients and understanding what factors predict QOL is important in being able to better treat this population.

Purpose of the Study

The purpose of this study was to determine whether cognitive distortions, social support, and/or levels of coping skills predict QOL in women with SLE. It was proposed that QOL would be predicted by a linear combination of distorted thinking, social support, and levels of coping. Understanding this relationship may illustrate the need for

health care professionals in primary care offices, specialty clinics, and other settings to receive better training to implement specific therapeutic interventions to modify SEL-related dysfunctional thinking and enhance support in an effort to promote effective coping skills and improve the quality of life of those who SLE.

Literature Review

Systemic lupus erythematosus. SLE is an autoimmune disease that causes a chronic inflammatory condition. The inflammation triggered by SLE can affect many organs in the body, including the skin, joints, kidneys, lung, and nervous system. SLE has a wide range of symptoms. The most common symptoms are joint pain, skin rash, and fever. Symptoms can develop slowly or appear suddenly. Many patients with SLE have flares, in which symptoms suddenly worsen and then settle down for long periods (Somers, Thomas, Smeeth, Schoonen, & Hall, 2007).

SLE is a chronic and relapsing inflammatory disease. It is marked by periods of remission (no symptoms) that alternate with flares of active disease when symptoms suddenly worsen. Flares tend to diminish after menopause (Fayyaz et al., 2015). Symptom-free periods can sometimes last for years, but the course of SLE is unpredictable and varies greatly from person to person. Some patients have mild forms of lupus with occasional skin rashes, fever, fatigue, or joint and muscle aches. Sometimes lupus remains mild, but other times it may become more severe menopause (Fayyaz et al., 2015). Severe lupus involves serious health complications and extensive internal organ damage, including damage to the heart, lungs, kidneys, and brain.

Prevalence. Studies in the United States conducted between 1950 and 2012 reported an increasing incidence of SLE. Reported values for the incidence and

prevalence of SLE vary considerably worldwide. In the United States, the prevalence of SLE ranges from 3.2 to 517.5 cases per 100,000 individuals, in contrast to prevalence in India being 3.2 per 100,000 and the prevalence among Afro-Caribbean people living in the United Kingdom being 517.5 per 100,000 (Somers et al., 2007).

Two unique and particularly comprehensive strategies for case ascertainment in SLE are capture-recapture methods and the community-oriented program for control of rheumatic diseases (COPCORD) approach. Capture-recapture methods evaluate the completeness of case ascertainment by estimating the number of cases that are missed when multiple data sources are used for data analysis. Two U.S. studies using this methodology derived almost identical incidence and prevalence values: the Michigan Lupus Epidemiology and Surveillance Program reported an incidence of 5.5 per 100,000 per year and a prevalence of 72.8 per 100,000 and the Georgia Lupus Registry reported an incidence of 5.6 per 100,000 per year and a prevalence of 74.4 per 100,000. Other studies using these approaches provides incidence estimates of 1.0 per 100,000 per year in Denmark and prevalence estimates of 21.9 to 28.3 per 100,000 in Denmark and 25.4 per 100,000 in Ireland (Alamanos et al., 2003).

Trends and patterns. Despite variations in the reported incidence and prevalence rates of SLE, apparent trends have emerged. SLE typically presents between the ages of 15 and 45 years, with a 9 to 1 ratio of female to male patients. Ethnic disparities are also widely recognized, with non-White populations generally having higher incidence and prevalence of SLE compared to White populations. For example, in the U.S., the incidence and prevalence of SLE in African Americans is approximately two to five times higher than in European Americans. In the U.K., the prevalence of SLE is six to eight

times higher in individuals of African ancestry and in Indo-Asian people than in White populations. The disease is also two to four times more common among Aboriginal individuals compared to non-Aboriginal individuals living in Australia, Canada, and the U.S. The incidence and prevalence of SLE is also higher in other populations that include individuals of African, Asian, and Aboriginal ancestry (Alamanos et al., 2003).

Diagnosis. Because SLE can have a wide variety of symptoms and different combinations of organ involvement, no single test establishes its diagnosis. To help doctors improve the accuracy of the diagnosing SLE, 11 criteria were established by the American Rheumatism Association (D'Cruz et al., 2007). Some individuals suspected of having SLE may never develop enough criteria for a definite diagnosis. Other people accumulate enough criteria only after months or years of observation. For individuals who meet four or more of these criteria, the diagnosis of SLE is strongly suggested. Nevertheless, health care providers in some settings may diagnose of SLE in people with only a few of these classic criteria, and treatment may sometimes be instituted at this stage. Among people meeting minimal criteria, some may later develop other symptoms, whereas others may not (Agmon-Levin, Mosca, Petri, & Shoenfeld, 2012).

As stated, there are 11 criteria used for diagnosing SLE: (a) malar (over the cheeks of the face) or "butterfly" rash; (b) discoid skin rash (patchy redness with hyperpigmentation and hypopigmentation that can cause scarring); (c) photosensitivity (skin rash in reaction to sunlight [ultraviolet light] exposure); (d) mucous membrane ulcers (spontaneous sores or ulcers of the lining of the mouth, nose, or throat); I arthritis (two or more swollen, tender joints of the extremities); (f) pleuritis or pericarditis (inflammation of the lining tissue around the heart or lungs, usually associated with chest

pain upon breathing or changes of body position); (g) kidney abnormalities (abnormal amounts of urine protein or clumps of cellular elements called casts detectable with a standard urinalysis; (h) brain irritation (manifested by seizures [convulsions] and/or psychosis, referred to as "lupus cerebritis"); (i) blood abnormalities, including blood count abnormalities (low white blood count [WBC], red blood count [RBC], or platelet count on routine complete blood count testing), leukopenia, anemia, and thrombocytopenia, each of which are detectable with standard complete blood count testing (CBC); (j) immunologic disorder as indicated by abnormal immune tests (including anti-DNA or anti-Sm [Smith] antibodies, falsely positive blood test for syphilis, anticardiolipin antibodies, lupus anticoagulant, or positive LE prep test); and (k) antinuclear antibodies (positive ANA antibody testing indicating antinuclear antibodies in the blood; Agmon-Levin et al., 2012).

Ultimately, in patients with kidney disease from SLE (lupus nephritis), a kidney biopsy may be necessary to both define the cause of the kidney disease as being lupus-related as well as to determine the stage of the kidney disease in order to optimally guide treatments. Kidney biopsies are often performed by fine-needle aspiration of the kidney under radiology guidance, but in certain circumstances, a kidney biopsy can be done during an open abdominal operation (Agmon-Levin et al., 2012).

In addition to the 11 criteria, other tests can be helpful in evaluating people with SLE to determine the severity of organ involvement. These include routine testing of the blood to detect inflammation (for example, the erythrocyte sedimentation rate [ESR] and the C-reactive protein [CRP]), blood-chemistry testing, direct analysis of internal body fluids, and tissue biopsies (D'Cruz et al., 2007). Abnormalities in body fluids (joint or

cerebrospinal fluid) and tissue samples (kidney biopsy, skin biopsy, and nerve biopsy) can further support the diagnosis of SLE. The appropriate testing procedures are selected for the patient individually by their doctors (Agmon-Levin et al., 2012).

Prognosis. The idea that lupus is generally a fatal disease is incorrect. Medical science has not yet developed a method for curing lupus, and there are cases in which people have died from SLE complications; however, taking medication(s) as prescribed, knowing when to seek help for unexpected side effects of medications or new manifestations of lupus, and following the physicians' instructions have improved the prognosis of individuals diagnosed with SLE (Abu-Shakra et al., 2005)

Because of more effective and aggressive treatments, the prognosis for SLE has improved markedly over the past two decades. Treatment early in the course of the illness that controls initial inflammation can help to improve long-term outlook. Over 95% of people with lupus survive at least 10 years (Shelman & Merrell, 2006).

Physical impact of SLE. Almost 85% of patients with SLE experience problems associated with abnormalities in the blood, and about half of patients with SLE are anemic. Between 34% and 42% of patients with SLE have antiphospholipid syndrome (APS). This is a disorder of blood coagulation related to the presence of autoantibodies called lupus anticoagulant and anticardiolipin. APS can cause blood clots, which most often occur in the deep veins of the legs, a condition called deep vein thrombosis. Patients with SLE and other autoimmune disorders have a greater risk for developing lymph system cancers such as Hodgkin's disease and non-Hodgkin's lymphoma (Konya, Paz, & Tsokos, 2014).

The risk for cardiovascular disease, heart attack, and stroke is much higher than average in patients with SLE, and heart disease is a primary cause of death. The chronic inflammation associated with SLE can cause plaque build-up in the heart's arteries (atherosclerosis), which can lead to coronary heart disease and heart attack. SLE also affects blood vessels and circulation. In addition, SLE treatments (particularly corticosteroids) can affect cholesterol, weight, and other factors that harm the heart (Konya et al., 2014).

Inflammation of the lung tissue is called lupus pneumonitis. It can be caused by infections or by the SLE inflammatory process. Symptoms are the same in both cases: fever, chest pain, labored breathing, and coughing. Rarely, lupus pneumonitis becomes chronic and causes scarring in the lungs, which reduces their ability to deliver oxygen to the blood (Konya et al., 2014).

Kidney complications, such as inflammation of the kidneys (lupus nephritis), are common in SLE. About one third of patients have lupus nephritis at the time of diagnosis and more than half develop it within 10 years after lupus symptoms begin. In its early stages, lupus nephritis can cause fluid build-up leading to swelling in the extremities (feet, legs, hands, arms) and overall weight gain (Konya et al., 2014). If left untreated, lupus nephritis may progress to complete kidney failure (end-stage renal disease).

Nearly all patients with SLE report some symptoms relating to problems that occur in the central nervous system (CNS), which includes the spinal cord and the brain. Symptoms vary widely and may overlap with psychiatric or neurologic disorders. They may also be caused by of some of the medications used for treating SLE. The most serious CNS disorder is inflammation of the blood vessels in the brain (CNS vasculitis),

which occurs in about 10% of patients with SLE. Fever, seizures, psychosis, and even coma also can occur (Konya et al., 2014).

Infections are a common complication and a major cause of death in all stages of SLE. Patients are not only prone to ordinary bacterial and viral infections, but they are also susceptible to fungal and parasitic infections, which are common in people with weakened immune systems such as those with SLE. They also face an increased risk for urinary tract, herpes, salmonella, and yeast infections. Corticosteroid and immunosuppressant drug treatments used for SLE also increase the risk for infections (Konya et al., 2014).

Many patients with SLE suffer gastrointestinal problems, including nausea, weight loss, mild abdominal pain, diarrhea, and gastroesophageal reflux disorder (heartburn). SLE can also affect organs located in the gastrointestinal system, such as the liver, gallbladder, pancreas, and bile ducts (Konya et al., 2014).

Patients with SLE often experience muscle aches and weakness. SLE can also cause pain, stiffness, and swelling in the joints. Notably, unlike in rheumatoid arthritis, the arthritis caused by SLE almost never leads to destruction or deformity of joints. In addition, patients with SLE commonly experience reductions in bone mass density (osteoporosis) and have a higher risk for fractures, irrespective of taking corticosteroids (which can increase the risk for osteoporosis; Konya et al., 2014).

Neurocognitive impact of SLE. Cognitive impairment (CI) in SLE is characterized by deficits in attention, learning and recall, verbal and nonverbal fluency, language, visuospatial skills, executive functions, and motor dexterity, and is probably due to damage of the fronto-subcortical circuits (Kozora, Thompson, West, & Kotzin,

1996). CI in SLE patients has been found in between 3% and 80% of patients (Sanna et al. 2013).

Economic impact of SLE. Patients with severe presentations have been found to use more health care resources over a 2-year follow-up period, and medical imaging and biopsies were performed more frequently in patients with severe symptoms (95% versus 77%; $p = .002$; Zhu, Tam, & E. K. Li, 2011). Further, corticosteroids (96% versus 45%; $p = .001$), immunosuppressants, (93% versus 70%; $p = .003$), and antihypertensives (89% versus 45%; $p = .001$) were prescribed more frequently in patients with severe presentations of the disease (Zhu et al., 2011). Overall, specialist visits occurred more frequently in patients with severe disease presentations, particularly to ophthalmologists (54% versus 17%; $p = .001$), cardiologists (32% versus 13%; $p = .023$), nephrologists (54% versus 13%; $p = .001$), psychiatrists (14% versus 0%; $p = .006$), and internists (32% versus 11%; $p = .011$). Inpatient stays and ER visits also occurred more frequently in patients with severe presentations compared to patients with non-severe presentations (59% versus 19% and 48% versus 26%, respectively; Zhu et al., 2011).

Results have shown that SLE is associated with substantial economic burden in terms of health care resources utilization, as well as losses of productivity due to work capacity impairment (Carls et al., 2009). Direct medical costs, indirect costs due to absenteeism, and indirect costs due to short-term disability in patients with SLE were estimated at $21,499, $3,824, and $2,474, respectively, compared with $8,008, $4,430, and $1,169, respectively, in persons without SLE (Zhu, Tam, V. W. Lee, K. K. Lee, & E. K. Li, 2009b). Generally, costs for inpatient care represented the largest proportion of direct costs, suggesting that at least 17% and up to 56% of annual direct costs were

incurred by less than 27% of the population (Panopalis et al., 2008). Up to 56% of direct annual costs were incurred by less than 27% of the population (Panopalis et al., 2008). Furthermore, the estimates of indirect costs are most likely to be underrated because these studies rarely take into account the productivity losses incurred by unpaid caregivers (Fautrel & Guillemin, 2002). Among cost predictors, poor physical or mental health, low social support, high education level, unemployment, and high disease activity were associated with high indirect costs (Pelletier, Ogale, Yu, Brunetta, & Garg, 2009). In regard to the impact of lupus flare ups (exacerbations of the disease) on costs of SLE, patients with flares incur significantly higher direct and indirect costs compared with those without flares (Lacaille, Clarke, Bloch, Danoff, & Esdaile, 1994). In addition, multi-organ flares or renal/neuropsychiatric flares have been found to be more costly than single-organ flares or other minor organ flares (Sutcliff, Clarke, Taylor, Frost, & Isenberg, 2000).

Cognitive distortions and SLE. The cognitive model posits that thinking patterns influence behavioral, emotional, and even physiological responses. A. T. Beck et al. (1979) described depression as a thinking disorder characterized by specific systematic cognitive errors. These systematic thinking errors are believed to result in erroneous thoughts, or cognitive distortions (A. T. Beck, 1967). A. T. Beck originally identified six cognitive distortions: arbitrary inference, selective abstraction, overgeneralization, magnification and minimization, personalization, and absolutistic, dichotomous thinking. Since the introduction of A. T. Beck's six original cognitive distortions, much attention has been given to thinking patterns in clinical populations. Burns (1980, 1990) went on to add to and simplify A. T. Beck's six original cognitive

distortions as well as to borrowing from Ellis (1962, 1976), ultimately identifying 10 cognitive distortions. Burns's greatest contribution in this realm may have been presenting these concepts in a way that a typical patient could readily understand and relate. These 10 distortions are all-or-nothing thinking, discounting the positives, emotional reasoning, jumping to conclusions, labeling, magnification, mental filter, overgeneralization, blaming and personalization, and should-statements (Burns, 1980, 1990). Others have identified even more thinking errors, such as comparison, externalization of self-worth, and perfectionism (Freeman & DeWolf, 1989; Freeman & Oster, 1999).

Several instruments have been designed to clinically assess the construct of cognitive distortions. These instruments include the Dysfunctional Attitude Scale (DAS; Weissman, 1979; Weissman & A. T. Beck, 1978), the Cognitive Bias Questionnaire (CBQ; Krantz & Hammen, 1979), the Automatic Thoughts Questionnaire (ATQ; Hollon & Kendall, 1980), the Cognitive Error Questionnaire (CEQ; Lefebvre, 1981), the Cognitive Distortion Scale (CDS; Briere, 2000), and the Inventory of Cognitive Distortions (ICD; Yurica & DiTomasso, 2001). These instruments vary in both clinical usage and distortions assessed, with the ATQ, DAS, and CEQ designed specifically for use with individuals diagnosed with depression. Inconsistencies in regard to the type and number of distortions assessed impacts clinical utility, as the DAS, CBQ, ATQ, CEQ, and CDS do not measure all distortions found in the literature.

Major depression is one of the most frequent psychiatric disorders observed in patients with SLE, with point prevalence rates between 10.8% and 39.6% (Shapiro, 2007). This is much higher than in the general population. Researchers sought to

determine the prevalence of moderate or severe depressive symptoms and to determine factors associated with these depressive symptoms in a large cohort of patients with SLE (Bachen, Chesney, & Criswell, 2009). Researchers found that 41.7% of patients reported moderate to severe depressive symptoms, consistent with previous reports highlighting the significance of depression in this population (Stojanovich, Zandman-Goddard, Pavlovich, & Sikanich, 2007; L. Zhang, Fu, Yin, Q. Zhang, & Shen, 2017).

Coping skills and SLE. In the field of health psychology, there are two major types of coping strategies: problem-focused (aimed at doing something active to modify a stressful situation, namely directed at reducing the threats and losses due to the illness) and emotion-focused (aimed at thinking or feeling in a different way about a stressful situation, namely directed at reducing the negative emotional consequences; Lazarus, 1993). Another distinction present in the literature is between active coping (behavioral or psychological efforts to change the stressful situation or the way one thinks or feels about a stressful situation) and avoidant coping (behaviors, such as drug use, or mental conditions, such as daydreaming about things other than the stressful event, that move away from the stressful event; Holahan & Moos, 2007).

Appraisal of stress has been related to flares in SLE (Birmingham et al., 2006). Recommendations for lupus patients to reduce perceived stress are based on numerous studies establishing the association between daily stress and disease exacerbation. For example, Peralta-Ramírez et al. (2004) evaluated 58 patients with lupus (46 with SLE and 12 with CCL) for 6 months and found that chronic stress worsened the symptoms of the disease to the greatest degree, and this was observed in up to 74% of patients. They also

found that 21% of patients with higher levels of the disease experienced deterioration 1 day after stress was increased.

Once an event has occurred and been appraised as a stressor, the second process relates to how the individual self-regulates and reduces stress, referred to as ‘‘coping’’ (Birmingham et al., 2006). Some of these coping strategies may prove beneficial, whereas others may instead prove to be ‘‘maladaptive’’ or less effective (Lazarus, 2000).

A meta-analysis showed emotion-focused strategies to be less effective and to be related to poor mental health in comparison to problem-focused coping (Penley, Tomaka, & Wiebe, 2002). In addition, disengagement coping is considered a psychological risk factor or a nonadaptive response to stressful events (Bricou et al., 2006). The course of the disease and the mental well-being of SLE patients have been shown to be influenced by coping strategies applied; disengaging and emotional coping styles have been described to interfere with the course of the disease, including patients' mental well-being and the QOL (Bricou et al 2006).

Anxiety and depression, which are frequently caused by daily stress, are the most prevalent psychological disorders experienced by lupus patients, affecting up to 40% of patients (Fonseca, Bernardes, Terroso, de Sousa, & Figueiredo-Braga, 2014). Furthermore, it is evident that lupus patients are dissatisfied with the treatment of both these disorders, indicating that lupus is currently being mismanaged and that patients' concerns are not being dealt with adequately (Figueiredo-Braga et al., 2018). These disorders, together with the chronic nature of the disease and its implications, not only affect the patient's physical and psychological well-being, but they also seriously limit

his or her QOL. It is widely accepted that adequate coping strategies can improve the QOL of patients with lupus (Figueiredo-Braga et al., 2018).

CBT and SLE. Researchers conducted studies regarding the effectiveness of cognitive-behavioral interventions in improving psychosocial stress and enhancing the well-being of individuals with SLE (Greco, Rudy, & Manzi, 2004). The results suggested that such interventions significantly reduced stress, anxiety, and depression, considerably improved QOL, and reduced some somatic symptoms (Greco et al., 2004). With regard to the emotional variables, it should be highlighted that, in addition to initially high levels of chronic stress, SLE patients have shown levels of anxiety and moderate levels of depression that were higher than average in the general population (Segui et al., 2000). After therapy, levels of anxiety and depression among patients treated with CBT were considerably lower and even fell below the population average (A. T. Beck, Steer, & Garbin, 1988).

Social support and SLE. Individuals with SLE can feel alone and isolated, and negative responses to their diagnosis such as disbelief or minimizing the problem might deter them from disclosing or seeking support from others in their social networks (Coursaris & Lin, 2009). Improving awareness of SLE in the general population and also for general practitioners or non-specialist treatment providers might have benefits for SLE patients (Revenson, 1993). In particular, increasing awareness of the subjective symptoms of lupus could help patients feel that their illness is understood by those involved in SLE treatment. In general, the findings suggest that lupus support groups are a potentially valuable source of informational and emotional support (Somers et al., 2014). Support groups have been shown to help buffer the feelings of isolation brought

on by a lack of understanding from patients' other social connections and, thus, may especially aid emotion-focused coping (Corcoran & Wall, 2000).

For many reasons, Internet-mediated communication has become popular for patients suffering of various health conditions, mainly due to the increasing ease of its use and accompanied by reduced costs (Mazzoni & Cicognani, 2011). Internet forums currently represent an opportunity for sharing experiences and social support among patients with chronic conditions, including SLE (Mendelson, 2003). A study was conducted to describe the demand and supply of social support through the Internet in relation to the description of personal illness experiences. All the posts (118) from an Italian forum for SLE patients were collected and analyzed, combining qualitative content analysis with statistical textual analysis. The results showed different purposes for posts: starting new relationships, seeking information, receiving emotional support, and giving contributions (Mazzoni & Cicognani, 2014).

Quality of life following diagnosis. QOL among SLE patients is an area of great interest to patients, family members, researchers, and health professionals in specialty and primary care settings. Although SLE can cause major organ damage, there are also many symptoms that, although they do not lead directly to major morbidity, can have a significant impact on a patient's life, including fatigue, chronic pain, sleep disturbances, headaches, and hair loss (Gallop et al., 2012). In part as a result of this, health-related quality of life (HRQOL) is generally poorer in patients with SLE than in the general population, and the reductions are similar to, or even exceed, those for other chronic diseases (McElhone, Abbott, & Teh, 2006).

Patients with SLE report reductions in all aspects of HRQOL, including physical and mental health, vitality, pain, and social and emotional functioning. HRQOL is influenced by a complicated interplay between disease and environmental factors, and determinants include disease manifestations, particularly fatigue, disease activity, and damage accrual, as well as the patient's level of helplessness and ability to cope with the disease. Multiple other symptoms have been associated with poor HRQOL, including depression, anxiety, and neuropsychiatric and cutaneous manifestations.

Over the last decade, survival of patients with SLE has significantly improved (Trager & Ward, 2001). Moreover, many studies demonstrated that patients' HRQOL depends on treatments' efficacy, such as the efficacy of corticosteroids and hydroxychloroquine on psychosocial factors such as quality of social relationships and perceived self-efficacy in the management of the disease (Sutanto et al., 2013). A recent literature review showed that social relationships have an impact on physical and psychological components of SLE patients' HRQOL. Most of the literature on social support and self-efficacy as predictors of patients' HRQOL is based on cross-sectional studies, which limits attempts to determine cause and effect relationships. Unlike cross-sectional studies, this longitudinal, prospective study aimed to evaluate the independent contribution of social support and self-efficacy to patients' subsequent HRQOL after controlling for patients' prior HRQOL.

Chapter 2: Hypotheses

This study tested four hypotheses. Based on the existing literature, the following hypotheses were developed:

Hypothesis 1

It was hypothesized that there would be a negative linear correlation between frequency of distorted thinking and QOL.

Hypotheses 2

It was hypothesized that there would be a positive significant correlation between social support and QOL.

Hypotheses 3

It was hypothesized that levels of coping would be positively correlated with QOL.

Hypotheses 4

It was hypothesized that the linear combination of cognitive distortions, social support, and levels of coping would significantly predict level of QOL.

Chapter 3: Method

Design

A cross-sectional correlational/regression design was employed (a) to assess the psychometric properties of the ICD by comparing total scores on this instrument with total scores on the World Health Organization Quality of Life-BREF instrument (WHOQOL-BREF), (b) to investigate the relationship between QOL as measured by the WHOQOL-BREF and level of coping skills as measured by the Brief COPE, (c) to investigate the relationship between QOL as measured by the WHOQOL-BREF and levels of social support as measured by the by the Social Support Behavior Scale (SSB), and (d) to test the predictive capacity of three predictors on QOL.

Participants

The total sample consisted of 62 women ranging in age from 18 to 55 years. The sample size is based on Tabachnick and Fidell's recommendation for a medium effect size, at the .05 level of significance with 80% power.

Inclusion criteria. Participants were required to meet predetermined conditions in order to be included in this study. First, participants had to be diagnosed with SLE for at least one calendar year prior to the commencement of the study. Second, participants were required to be between the ages of 18 and 55. Third, participants must have had at least a self-reported eighth-grade education and be fluent in written and spoken English to ensure they would be able to read and understand the measures.

Exclusion criteria. Participants were excluded from the study if they reported that they did not have SLE diagnoses, were below 18 years of age or older than 55, were unable to speak and read English fluently, or had less than an eighth-grade education.

Participants were also excluded if they did not fill out the questionnaires in their entirety. Prior to completing the surveys, each participant completed five eligibility questions. If they answered "No" to any of the preliminary questions, they were not eligible to complete the surveys and the survey was discontinued immediately.

Measures

Study materials included a cover letter and four self-report questionnaires. The cover letter informed the potential participants about the general purpose of the study, potential risks of participation, and the right to withdraw from the study at any time. The questionnaires consisted of the ICD (Yurica & DiTomasso, 2001), the WHOQOL-BREF (WHOQOL group, 2004), the MSPSS (Zimet, Dahem, Zimet, & Farley, 1988) and the Brief COPE (Carver, 1997). The total administration time for the survey packet was approximately 20 to 30 minutes.

Inventory of Cognitive Distortions. The ICD is a 69-item self-report survey designed to measure the frequency of 11 factor-analyzed cognitive distortions (Yurica & DiTomasso, 2001). Items are scored on a 5-point Likert scale, ranging from 1 (never) to 5 (always). Total possible scores range from 69 to 345. Lower scores reflect lower frequencies of cognitive distortions, whereas higher scores reflect more frequent distortions. The score is obtained through addition of the numerical ratings.

The ICD has excellent internal consistency and test-retest validity. The ICD was originally designed for and validated with an adult clinical population exhibiting symptoms of depression and anxiety. One study examining the frequency of cognitive distortions in medical patients found high internal consistency ($\alpha = .97$; Uhl, 2007). Yurica (2002) reported a test-retest reliability of .998 in a sample of 28 adults. Content

validity was established for the ICD during the construction of the instrument. A panel of three cognitive therapy experts reviewed and agreed unanimously on each of the 69 items (Yurica, 2002). In addition, convergent validity has been demonstrated, with the ICD correlating with measures of psychopathology and pervasive negative attitudes toward the self, world, and future. Yurica found that the ICD correlates with the Beck Depression Inventory (BDI-II; r = .70; A. T. Beck, Steer, & Brown, 1996), the Beck Anxiety Inventory (BAI; r = .59; A. T. Beck & Steer, 1990), and Weisman and Beck's Dysfunctional Attitude Scale (DAS; r = .70; Weissman & A. T. Beck, 1978).

The ICD has been identified as a useful tool for measuring cognitive distortions and patterns of dysfunctional thinking. It can be used for a variety of reasons in CBT settings, including intake assessment and as a marker for treatment progress gleaned through baseline and outcome assessment. It has also been used for research in establishing relationships between cognitive distortions and psychological diagnoses for both clinical syndromes and personality disorders (Rosenfield, 2004), anxiety and depression in adults diagnosed with ADHD (Strohmeier, 2013), parental stress and child psychopathology (Kennedy, 2012), and psychological and behavioral outcome factors in medical patients (Uhl, 2007), family medicine outpatients (Goins, 2008), and overweight and obese individuals (Shook, 2010), among others.

WHOQOL-BREF. The WHOQOL-BREF is a 26-item self-report survey designed to measure QOL (WHOQOL Group, 1998). The 26 items are divided into two global QOL item categories and 24 specific QOL item categories. The scale consists of four domains: physical health, psychological health, social relationships, and

environment. Items are scored on a 5-point Likert scale, ranging from 1 (not at all) to 5 (extremely).

Respondents are asked to answer how much each item pertains to them over the past 2-week period. The score is obtained by calculating the mean score for each domain, then multiplying the mean score by 4. Scores for each domain range from 4 to 20, which is comparable to the WHOQOL-100. Each domain score can be transformed to a scale ranging from 0 to 100, if desired. A low score reflects a low QOL and a high score reflects a high QOL. The first two items are examined separately, as these items assess the person's overall perception of QOL and health.

The WHOQOL-BREF demonstrates satisfactory internal consistency and discriminant validity among spinal cord injury (SCI) survivors (Jang, Hsieh, Wang, & Wu, 2004), as well as item-domain validity (r = 0.41 to 0.77), and moderate to high reliability (α = 0.74 to 0.87; Hill, Noonan, Sakakibara, Miller, & SCIRE Research Team, 2010). Test developers reported the Cronbach's α coefficients as follows: .80 for physical, .76 for psychological, .66 for social, and .80 for environment (WHOQOL Group, 1998). When tested for use with medical patients, the WHOQOL-BREF demonstrated internal consistency in three of four domains (Jang et al., 2004). The social relationships domain did not demonstrate high internal consistency (α = .55), likely due to the small number of items within this domain (3 items). Subscale correlations confirm construct validity among the physical health (0.55 to 0.73), psychological health (0.59 to 0.73), social relationships (0.65 to 0.77), and environmental (0.52 to 0.75) subscales (Hill et al., 2010).

When the WHOQOL-BREF was compared to the Short Form-36 (SF-36; Ware, Snow, Kosinski, & Gandek, 1993), both measures demonstrated very good internal consistency (Cronbach's α coefficients of 0.72 to 0.98 and 0.75 to 0.84, respectively), intra- and interrater reliability (intraclass correlation coefficients of 0.41 to 0.98 and 0.56 to 0.95), and convergent validity among the conceptually related domains (Lin, Hwang, Chen, & Chiu, 2007). The WHOQOL-BREF has lower ceiling and floor values than the SF-36.

The Brief COPE. Coping was measured by the Brief COPE (Carver, 1997). The Brief COPE consists of 14 2-item scales. Respondents mark their uses of each of the coping options in dealing with the stressful encounters in their current situations. The scale ranges from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). The Brief COPE can measure the following constructs: (a) problem-focused coping (including active coping [items 2 and 7], self-distraction [items 1 and 19], positive reframing [items 12 and 17], planning [items 14 and 25], and use of instrumental support [items 10 and 23]), (b) emotion-focused coping (including use of emotional support [items 5 and 15], behavioral disengagement [items 6 and 16], venting [items 9 and 21], religion [items 22 and 27], and substance abuse [items 4 and 11]). Four constructs do not fall into these categories: self-blame (items 13 and 26), humor (items 18 and 28), acceptance (items 20 and 24), and denial (items 3 and 8). The scores are not typically evaluated as an overall coping index. Test-retest reliability shows $r = .60$ and is considered acceptable, along with the validity at .72 (Carver, 1997).

Multidimensional Scale of Perceived Social Support. The Multidimensional Scale of Perceived Social Support (MSPSS) is a validated 12-item instrument designed to

assess perceptions about support from family, friends, and significant others. This scale was developed by Zimet, Dahem, Zimet, and Farley in 1988. The items are divided into factor groups relating to the source of support, with scores ranging from 1 to 7 on a Likert scale. High scores indicate high levels of perceived support and low scores indicate low levels of perceived support. This scale was studied and validated using adolescent and adult outpatient populations (Zimet et al., 1988). Social support is believed to contribute a moderating influence between stressful life events and depression.

Initial MSPSS reliability was demonstrated, with good internal reliability and good stability. The sample size was 275, with coefficient α for the subscales and scale as whole ranging from .85 to .91 and test-retest values ranging from .72 to .85 (Zimet et al., 1988). In addition, adequate MSPSS content validity was demonstrated by Zimet et al., (1988).

Procedure

This study was conducted online via SurveyMonkey in an effort to reach the specialized SLE female population and recruit individuals who otherwise may not have been able to participate due to limitations in mobility and/or lack of transportation. The responsible investigator created a research study announcement, flyer, and cover letter. The announcement informed prospective participants of the purpose of the study and expected duration of participation. The flyer informed potential participants of the purpose of the study, inclusion and exclusion criteria, anticipated duration, the Internet web address to access the study, and contact information for the researcher, advisor, and research coordinator. The cover letter included a description of the study, an explanation of what participation would entail, and a description of the risks and benefits of

participating. Participants were recruited on the Internet. The study announcement was posted to several discussion forums and online lupus support groups. In an effort to recruit more participants, prospective participants were requested to forward the survey link on to other interested individuals.

All participants were provided with a SurveyMonkey link and IP addresses were not recorded. If a potential participant clicked on the link, he or she was provided with an extensive explanation related to the conditions of participation, including that participation would be anonymous (with no potential for identifying or linking responses to the respondent), that participation was voluntary, that a person could withdraw from the study at any time without consequences, that the known risks were minimal (but that the person may find out something about himself or herself that could be mildly upsetting), that there would possibly be potential benefits to participation for others, that completing the questionnaires would make him or her eligible for a raffle to win one of two $50 gift cards, and that if he or she had any questions, he or she could reach out to the principal or responsible investigators.

Potential participants were asked to respond as to whether they understood the terms and conditions of participation and those who agreed to participate were given a series of inclusion/exclusion criteria-related questions. Those who met the inclusion criteria had the opportunity to participate. Those who did not were be informed that they did not meet eligibility to participate and were thanked. Once a participant completed all of the questionnaires, he or she was given an opportunity to participate in a raffle. Each participant was informed that he or she should e-mail the responsible investigator to participate and that these e-mails would not in any manner be tied to survey responses.

The responsible investigator composed a brief inclusion/exclusion demographic and diagnostic questionnaire, using standard questions that have been accepted for use with female SLE patients, to ensure inclusion criteria were met and exclusion criteria were not met. No identifying information was collected, and all participants remained anonymous. The measures being used in the study (ICD, WHOQOL-BREF, SSB, and COPE) were administered electronically, which allowed users to create and share questionnaires on the Internet and allowed respondents to remain anonymous. The researcher gained approval from the author of the ICD, Robert DiTomasso, authors of the WHOQOL-BREF, the World Health Organization, to use and administer the measures electronically for the purpose of this research.

Chapter 4: Results

In discussing the results of this study, it must be noted that the Brief COPE was modified in a manner that has not been used previously, which may have affected validity and reliability. When indicated, items were reverse scored and a total score for the scale was calculated as a measure of positive coping. Coefficient α for the entire scale was calculated to be .95, supporting the use of an overall coping index. Scores on the individual coping scales were not calculated as is usually done. As such, the results should be interpreted with caution.

Demographic Analyses

In this study, 100% of the participants were female and had been diagnosed with lupus for at least one 1 year prior to recruitment. Participants fell between the ages of 18 and 55 years. All participants reported having at least an eighth-grade educational level and reported being fluent in spoken and written English. Correlations, means, and standard deviations can be found in Table 1.

Table 1

Means and Standard Deviations for Variables the Coping, Cognitive Distortions, Social Support, and QOL

	N	Mean	Std. Deviation
ICD	62	215.9032	58.56024
WHOQOL	62	61.1935	22.72418
MSPSS	62	43.1452	17.08498
Brief Cope	62	61.3548	19.76012

Analysis of Hypotheses

All correlational findings are shown in Table 2. Hypothesis 1 predicted that there would be a significant negative relationship between the total score on the ICD and QOL measure. A Pearson correlation coefficient was computed and a significant negative relationship was found, $r = -.704$, $p < .001$. Based on the fact that including Hypothesis 1, there were four analyses conducted on the same set of data, a Bonferroni correction was calculated as .05 divided by 4 = .01. Using the Bonferroni correction, the finding for Hypothesis 1 was supported. The coefficient of determination revealed that 49.5% of the variability in scores on WHOQOL-BREF were attributable to differences in scores on the ICD. In other words, almost 50% of the variability in QOL is attributable to differences in distorted thinking.

Hypotheses 2 predicted that there would be a significant positive correlation between social support as measured by the MSPSS and scores on the WHOQOL-BREF. Bonferroni correction was calculated to be .01. As shown in Table 2, a Pearson correlation coefficient revealed a high and significant relationship between social support and quality of life, $r = .823$, $p < .001$. The coefficient of determination demonstrates that almost 68% of the variability in self-reported QOL is attributable to differences in social support.

Hypotheses 3 predicted that Brief COPE scores would be significantly and positively related to WHOQOL-BREF scores. The Bonferroni correction was calculated to be .01. As shown in Table 2, a Pearson correlation coefficient revealed a positive and significant correlation between these two variables, $r = .882$, $p < .01$. The coefficient of determination revealed that 77.7% of the variability in QOL is attributable to differences

in coping. It is important to note that in the calculation model, negative coping items (denial: items 3 and 8; substance use: items 4 and 11; behavioral disengagement: items 6 and 16; self-blame: items 13 and 26) were reverse scored, as noted above. Coefficient α for the entire scale was calculated to be .95, supporting the use of an overall coping index. Scores on the individual coping scales were not calculated as is usually done. As such, the results should be interpreted with caution.

Table 2

Correlations Between the Predictors and Criterion for Coping, Cognitive Distortions, Social Support, and QOL

	QOL	Coping	Cognitive Distortions	Social Support
Pearson Correlation	1	.882	-.704	.823
N	62	62	62	62
Sig. (1-tailed)	.000	.000	.000	.000

Hypotheses 4 predicted that the linear combination of coping, cognitive distortions, and social support would significantly predict QOL. Specifically, it was hypothesized that scores on the Brief COPE would predict higher QOL, scores on the ICD would predict lower QOL, and social support would predict higher QOL. In conducting this analysis, correlations of each predictor with the criterion were calculated and each of the predictor variables correlated with the QOL criteria (see Table 2). Based on this analysis, the decision was justified for including all three predictors into the regression equation; however, before utilizing the three predictors, a multicollinearity

analysis was conducted. First, Pearson correlations between the predictors were considered, and according to Field (2017), intercorrelations between predictors that fall around .80 or above may indicate multicollinearity. Of all of the predictors, MSPSS and the Brief Cope correlated, r = .80, Brief Cope and ICD correlated, r = -.705, and the ICD and the MSPSS scale correlated, r = .685. To further examine the potential for multicollinearity, variance inflation factors and tolerance statistics were considered using Field's criterion. Variance inflation factors greater than 10 would indicate a concern and tolerance statistics below .10 would be considered serious as indications for multicollinearity.

As shown in Table 3, in the present study, the tolerance levels and VIF values were considered appropriate. Therefore, multicollinearity was not considered a potential threat in the current study. In addition, the assumption of independent errors was tested with the Durbin-Watson statistic. According to Field (2017), the Durbin-Watson tests "for serial correlation between errors in a regression model . . . specifically whether adjacent residuals are correlated" (p. 740). Field stated that values less than 1 or greater 3 are concerning, and that the closer the value is to 2, the more likely an assumption will have been met. In the present study, the Durbin-Watson statistic was 1.78, indicating the assumption of independent errors was met. The results of the multiple regression analysis are shown in Tables 3, 4 and 5. Using the Brief COPE, ICD, and MSPSS scores as predictors revealed a multiple of .904 with a coefficient of determination .817. The adjusted coefficient of determination was .808, revealing very little if any shrinkage. The F value was significant at $p < .001$ and the overall ANOVA source table revealed a significant F. These findings reveal the set of predictors are significantly predicting the

criterion at a better than chance level. A test of the individual predictors revealed that only social support and coping made significant contributions to the prediction of the QOL. The linear combination of social support and coping is useful in predicting QOL. It should be noted that the histogram for QOL conforms relatively well to a normal distribution; however, there was some deviation from normality as noted on the pp-plot of standardized residuals. The scattered plot of QOL reflected regression standardized predicted values against regression standardized residuals, which supported a normal distribution and homoscedasticity.

Table 3

Model 1 Summary of Predictor Variables (Brief COPE, ICD Total Score, Social Support) to the Criterion Variable (QOL)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	Df1	Df2	Sig. F Change
1	.904	.818	.808	9.95494	.818	86.618	3	58	.000

Table 4

Overall Regression Analysis with Predictor Variables (Coping, Cognitive Distortions, Social Support) to the Criterion Variable (QOL)

Model		Sum of Squares	Df	Mean Square	F	Sig.
1	Regression	25751.826	3	8583.942	86.618	.000
	Residual	5747.852	58	99.101		
	Total	31499.677	61			

Table 5

Coefficients of Predictor Variables (Coping, Cognitive Distortions, Social Support) to the Criterion Variable (QOL)

Model	Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
	B	Std. Error	Beta	T	Sig	Tolerance	VIF
1(Constant)	11.814	11.760		1.005	.319		
ICDTotalSc	-.038	.032	-.097	-1.181	.243	.464	2.154
SocSupp	.378	.132	.284	2.865	.006	.320	3.121
BriefCope	.672	.117	.584	5.743	.000	.304	3.291

Chapter 5: Discussion

Lupus is a chronic disease that has increased in prevalence and awareness over the last two decades. With such increased awareness, more research has been conducted examining factors impacting the QOL of individuals with this disease. Although such research has been beneficial in uncovering various variables related to QOL within this population, many of the variables that have been identified (e.g., gender, age, presence of comorbid illness, etc.) cannot be modified within a clinical setting due to their fixed nature. In light of this, and to help improve the QOL of this group, the current study aimed to increase the understanding of factors which may be amenable to treatment. In particular, the relationship between cognitive distortions, social support, coping skills, and QOL in female individuals with SLE was examined.

The results of this study indicated that the QOL for a females with SLE is significantly associated with cognitive distortions (i.e., dysfunctional thoughts) along with social support and coping skills in the presence of medical symptoms. For females with SLE, psychological well-being is related to perception regarding the ability to manage obstacles and challenges, and to experiences of uncomfortable physical symptoms and distressing psychosocial issues.

The results of the present study further indicated that perceived QOL in regard to social relationships is influenced by the presence of a cognitive distortions, social support, and coping skills. Thus, although not inferring causality, the perceived nature of an individual's social QOL may be negatively affected by her belief that she cannot manage the problems in her life, and the presence of distressing physical symptoms associated with cognitive distortions.

This research illuminated the interaction between external and internal events, specifically, the role of the interpretation of events on an autoimmune disease such as lupus in relation to emotional processes and perceived well-being. These results may imply the importance of the role of CBT in potentially helping patients alter dysfunctional and distorted cognitions to improve QOL, learn efficient coping skills, and become active in helpful social support resources. Whereas past studies have assessed psychosocial issues associated with female SLE patients, these studies were limited by the use of measures that assess for only select disorders.

CBT interventions are well suited to reduce specific cognitive distortions in this population. Specifically, using cognitive restructuring for both emotional reasoning and decision making, clinicians can teach patients the cognitive model, that thoughts influence emotional states and behaviors reciprocally, helping them identify and challenge distorted and dysfunctional thoughts. Patients can learn to replace distorted or dysfunctional thoughts with more accurate or adaptive thoughts and can learn problem-solving skills to help them rely less on emotions for reasoning and decision making. Patients can also be taught to distinguish between fact versus an emotional state. Techniques such as a cost-benefit analysis, vertical descent, or the double-standard exercise can be useful tools to illustrate this concept (Leahy, 2003). Problem-solving therapy, which facilitates adoption of a more adaptive problem orientation, such as being optimistic in believing that one can cope with and resolve feelings of hopelessness and doubt rather than believing one's situation will never improve, is another avenue by which one can learn to challenge emotional reasoning and decision making and improve one's life (A. M. Nezu & C. M. Nezu, 2001).

For the cognitive distortion of comparison to others, clinicians can help patients to refrain from comparing themselves to others and shift their focus to personal strengths and retained abilities, which may permit them to think more adaptively. Leahy (2003) suggested the use of positive tracking, or keeping a journal of positive experiences or actions to help shift focus to positive qualities rather than perceived shortcomings. Patients can then praise themselves for their positives, which may serve to increase positive behaviors. Identifying and correcting these frequent distortions can enhance QOL and facilitate adjustment to disability. In positive psychology, interventions aim to help people shift their focus from misfortune and what has gone wrong in life to blessings and what has gone right (Seligman, Rashid, & Parks, 2006). One such positive psychology technique that seems particularly well suited to this population is the three blessings exercise, in which lupus patients can be encouraged to identify three things that they are most happy with at the end of the day and how they contributed to the three blessings going well, in order to add gratitude and optimism to life, in addition to increasing self-efficacy by recognizing their own contributions.

Findings and Clinical Implications

Cognitive distortions and quality of life. The current study found that high levels of distorted thinking were highly correlated with lower QOL, which is a known to highly correlate with depression. These results corroborate much of what has been demonstrated previously in the literature (Shapiro, 2007). These findings suggest that when unhelpful thinking patterns such as all-or-nothing thinking, discounting the positives, emotional reasoning, jumping to conclusions, labeling, magnification, mental filter, overgeneralization, blaming and personalization, and should-statements are present

in female adults with lupus, these individuals often present and report experiencing an overall lower QOL. As such, clinically, it is important for clinicians to screen for these cognitive distortions when treating female adults with lupus and to modify treatment accordingly.

Social support and quality of life. The present study found there to be a high and significant relationship between social support and QOL. The role of social support in chronic disease, such as cancer, has been widely researched; however, its impact on SLE has not been well confirmed. Sutcliffe et al. (2001) reported a higher level of perceived social support was associated with better QOL, except for in the role-emotional domain. This study's results indicate social support is a contributor of better QOL among lupus patients, perhaps due to the buffering properties of social support. Social support can buffer the effects of stressful life events leading, subsequently, to higher QOL. Clinically, social support can help a patient adjust to life with a disease. Individuals who have higher levels of perceived social support can manage situations more effectively, even in the most difficult situations, whereas lower levels of perceived social support contribute to poor outcomes (Zheng et al., 2009).

Coping and quality of life. The present study found there to be a strong and significant relationship between coping and QOL. Coping can help patients become stronger to deal with the disease and other important life events, relieving their suffering. This study's results indicate positive coping strategies are a contributor of better QOL among lupus patients. These finding support some of what has been demonstrated previously in the literature (Navarrete-Navarrete et al., 2010). Psychotherapeutic treatment can lead patients to better cope with illness and increase adherence to medical

treatment. In past research, it was shown that after treatment, patients handled their bodies and diseases differently, minimizing the importance of symptoms that were felt before as severe and harmful, which interfered in their daily activities (Navarrete-Navarrete et al., 2010). Incorporating occupational activity, treatment, humor, and self-image in female lupus patients may lead to positive changes in coping strategies and be effective in improving QOL.

From a clinical perspective, the results further underscore the importance of appropriate psychological assessments during the course of medical treatment with female adults with lupus. The presence of lack of support, cognitive distortions, and poor coping in adult female lupus patients is likely to predict frequent episodes of depression and a poor QOL. This increased frequency of cognitive distortions may exacerbate many of the functional difficulties already experienced by female adults with lupus, which are well-documented in the literature impact mood, and further decrease QOL (Weissman, 1979). Therefore, it is essential for medical clinicians to be aware of the impact mood disorders as well as maladaptive personality features can have on their clients' clinical presentations and life difficulties. Physicians can refer patients to mental health clinicians who can provide treatment accordingly so that cognitive distortions can be addressed adequately. CBT is uniquely qualified in this regard. According to J. S. Beck (2011), cognitive distortions are the result of a "systematic negative bias [or inaccuracy] in . . . cognitive processing" (p. 179) found in individuals suffering with a wide variety of psychiatric disorders. Underlying maladaptive core beliefs and intermediate beliefs give rise to negative or otherwise distorted automatic thoughts. These maladaptive automatic thoughts, which are often distorted, can in turn lead to psychiatric disorders such as

anxiety and depression (Mathews & MacLeod, 2005). Successful CBT involves identification of the cognitive distortions and dysfunctional core beliefs, and "direct modification of their core beliefs as soon as possible" so that clients may begin to view their current and future problems more adaptively (J. S. Beck, 2011, p. 35). As such, the ICD may be a particularly advantageous measure to use during the course of specialist visits for medical treatment for female adults with lupus, as it identifies cognitive distortions, which may quickly alert medical providers to refer patients to obtain psychological counseling, treatment, and/or social support resources.

The role of the psychologist. Based on the findings of this study, living with lupus can have a profound effect on a person's mental and emotional well-being. Therefore, it is imperative that a psychologist be involved in assessing the individual's and family's psychological status and ability to cope with the unpredictable nature and changing health status associated with lupus. The psychologist may be able to tailor a treatment plan to meet the needs of the patient and provide a wide range of interventions. Psychological therapy may include short-term interventions such as CBT or other evidence-based treatments for depression, anxiety, and poor self-image; treatment for sleep disturbance; mindfulness training; guided imagery; breathing exercises; relaxation training; and/or exercise therapy. These interventions have also been beneficial for dealing with other adjustment issues and/or improving symptom management and functioning, crisis management, and reducing maladaptive behaviors.

Studies have shown that a combination of psychoeducational and psychotherapeutic interventions significantly improve outcomes in patients with lupus (Magro-Checa, Zirkzee, Huizinga, & Steup-Beekman, 2016). Some patients can benefit

from training in behavioral charting. Identifying patterns and associations between flares, stressors, pain, and physical activities can be helpful and may increase patients' perceived control and hope for the future. Exercise can increase mobility and/or flexibility by helping to build muscle tone and strength, and low-impact and moderate activities, such as stretching, walking, or aqua aerobics, may benefit management of the disease. Appropriately addressing the mental health issues associated with SLE through patient education programs, psychological assessment and interventions has been shown to reduce healthcare costs and lessen the complications of the disease (Danoff-Burg, & Friedberg, 2009).

The psychologist may also interact with rheumatologists and psychiatrists when combined psychological and medication treatments are needed. The psychologist can be involved in program planning, validation, and research, as well as the development and validation of assessment measures. A neuropsychologist, who specialize in the functioning of the brain, should have the knowledge and training to become involved with persons with lupus when there are questions or concerns about changes in cognitive functioning.

Limitations

There are limitations in the present study that should be considered when evaluating the results. A major limitation of this study was the failure to obtain demographic characteristics of the sample. Although inclusion-exclusion criteria provide some information, the absence of other demographics precluded additional analysis and a more exact description of the sample. More specifically, it would have been useful to know each participant's specific age, age of onset of the diagnosis, year of diagnosis,

other psychiatric conditions, current involvement in and history of psychotherapy, psychotropic and other medications being taken, other medical conditions, marital status, and ethnicity.

An additional limitation to this study is that it would have been preferable to randomly counterbalance the order in which the questionnaires were presented to the participants. By not doing so, the results were limited by the possible order effects related to the presentation of the questionnaires in the standard order that was used. The potential impact of completing the questionnaires in a given order is, then, not distributed equally across the subjects. A related issue is that participants may have been fatigued by the end of the entire survey, which may have impacted the completion of the last questionnaire.

Another important challenge to note was the difficulty in securing participants for the study. There was a limitation related to self-selection, to the extent that there may be something unique about those who chose to participate. For example, these individuals might differ in some important ways on their level of impairment, distorted thinking, levels of available social support, coping, or QOL. This had implications for generalization of the findings. Due to the aforementioned lack of a demographic questionnaire, it was not possible to compare those who participated from those who met inclusion criteria but dropped out.

An additional notable limitation to the current study is that participation may be limited to those with Internet access, who visit lupus-related websites/discussion forums and attend lupus-related support events. This may lead to selection bias, as it is unknown whether female lupus patients who frequent these sites differ from lupus patients who do

not. For example, those with the most severe cases of lupus may not be physically able to access the Internet. Although using a convenience sample improved the ability to reach out to this specialized population, generalizability was threatened.

An added limitation of note involves the use of self-report measures, as these are reactive measures, and respondents may not have answered truthfully (Kazdin, 2003). Ideally, it could be useful to use multimethod approach with behavioral, physiological, and/or collateral data. Also, the WHOQOL-BREF, Brief COPE, MSPSS, and ICD have not validated for use with lupus patients. Regarding the ICD specifically, this population may require the use of a measure designed specifically for lupus patients that targets distortions related to the challenges resulting from the health condition. Unfortunately, no such measure exists.

Another limitation of the present study is that women with various clinical presentations of lupus were not examined within the study. It may be that women with particular subtypes or clinical manifestations (e.g., kidney complications as compared to gastrointestinal issues) of lupus could be more likely to present with cognitive distortions than those diagnosed with other subtypes. Examining subtypes could help explain the discrepancy between the current results and previous findings.

Future Directions

Because the current results are supportive of all of the proposed hypotheses, it will be especially important for future research to replicate and expand on the current findings. One particularly useful way to expand on the current findings would be to examine different lupus populations. For instance, future research should replicate this study in a community-based rheumatology clinic where there may be a sample more

representative of the average female adult with lupus, or where a more diverse sample could be obtained. Additionally, replicating this study with adolescents and older adults would be conceptually informative, to discover whether puberty or other age-related physical developmental milestones that become present over time impact coping, cognitive distortions, social support, and/or QOL.

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