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Development of a Systemic Lupus Erythematosus Knowledge Questionnaire: The Relationship Among Disease Proximity, Educational Exposure and Knowledge

Shelbie Sullivan
University of Wisconsin-Milwaukee

DEVELOPMENT OF A SYSTEMIC LUPUS ERYTHEMATOSUS KNOWLEDGE QUESTIONNAIRE: THE RELATIONSHIP AMONG DISEASE PROXIMITY, EDUCATIONAL EXPOSURE, AND KNOWLEDGE

by

Shelbie Lee Sullivan

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ABSTRACT

DEVELOPMENT OF A SYSTEMIC LUPUS ERYTHEMATOSUS KNOWLEDGE QUESTIONNAIRE: THE RELATIONSHIP AMONG DISEASE PROXIMITY, EDUCATIONAL EXPOSURE, AND KNOWLEDGE

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Shelbie L. Sullivan

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There are an estimated 1.5 million people living with systemic lupus erythematosus (SLE), a multisystem autoimmune disorder with a high risk of co-morbid health concerns. The psychological consequences of an SLE diagnosis result in increased daily stress, anticipated stigma, fears of rejection, and increased self-consciousness, all of which can decrease a patient's quality of life. In order to combat these negative experiences, attempts to increase accurate knowledge of SLE and extinguish SLE misconceptions must be made. The current study aimed to 1) create a medically informed SLE knowledge questionnaire; 2) determine the rate of community members' SLE knowledge; and 3) determine the relation that disease proximity and educational exposure have on community members' knowledge of SLE. This novel study is the first to create an SLE knowledge questionnaire and provide evidence that having a closer personal relation to SLE increases SLE knowledge, as does having learned about SLE in an educational setting.

To

my mother, my dear friend Samara,

and all those living with lupus – this is for you.

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Chronic disease affects nearly 50% of Americans, which means approximately 117 million people are living with at least one chronic condition (Ward, Schiller, & Goodman, 2014). Systemic lupus erythematosus (SLE) is one example of a chronic disease that has physical, psychological, financial and social implications for individuals who are diagnosed. According to the American Autoimmune Related Diseases Association (AARDA), in 2011 SLE cost around $20,000 a year per patient in direct and indirect healthcare costs. Nationally speaking, SLE costs somewhere between $2.2 billion and $9.6 billion dollars a year.

Systemic lupus erythematosus is a rare and complex multisystem autoimmune disorder where one's immune system is overactive and the body attacks its own organ systems (Mak, Ho & Lau, 2009; NIAMS, 2006). There are four specific variations of the illness cutaneous/discoid lupus, drug-induced lupus, neonatal lupus, and SLE. However, SLE is the most common diagnosis and makes up 90% of all broad lupus diseases. SLE is also most commonly referred to as "lupus," while the other variations are referred to by their specific name. Due to the complexity of SLE and the diagnostic process, prevalence rates are quite difficult to calculate. The Lupus Foundation of America (n.d) reports that there are approximately 1.5 million cases of lupus and 70% of these cases are SLE-specific. However, newer studies have attempted to gather statewide prevalence rates rather than national rates (Pons-Estel et al., 2010; Somers et al., 2014; Feldman, et al., 2013; Helmick et al., 2008). More recent researchers' findings estimate that there are 161,000 definite cases and another 322,000 probable cases of SLE to date (Helmick et al., 2008) and approximately 6 newly diagnosed cases per 100,000 people each year (Pons-Estel et al., 2010; Somers et al., 2014). This uncertainty about the true number of SLE cases makes getting appropriate treatments difficult because so many patients are not aware of their diagnosis.

The specific cause of this abnormal immune functioning is not fully understood; however, both genetics and environmental factors play a role in disease onset (Bensler & Silverman, 2007). The disease is considered an invisible chronic illness due to the manifestations being largely internal in nature (NIAMS, 2006; Parrondo, 2011). This label is given because patients experience unique challenges in their life when diagnosed with an invisible illness that threaten their quality of life (QoL; Brennan & Creaven, 2015; Sutanto et al., 2013). Patients diagnosed with SLE report excessive uncertainty, hopelessness, and helplessness related to the experience of their invisible symptoms (Beckerman, Auerbach, & Blanco, 2011). Patients are also at an increased risk for psychiatric conditions, which further decrease their QoL.

Patients often find that they must learn to identify and care for their physical symptoms quickly in order to manage their disease more effectively. This ability to monitor one's disease is often times difficult as symptom expression and severity is extremely unpredictable (NIAMS, 2006; Lau & Mak, 2009). Patients experience symptoms in flares, which is when symptoms occur in a variation of severity levels with a varying array of symptoms. The range of SLE symptom expression varies between mild disease activity and severe disease activity throughout patients' lives (NIAMS, 2006). It is estimated that 50% of SLE patients will also manifest severe complications of the disease: nephritis (kidney inflammation), vasculitis in the central nervous system (inflammation of brain and spine blood vessels), pulmonary hypertension (deterioration of lung capillaries), interstitial lung disease (lung tissue scarring causing breathing difficulties), and stroke (Parrondo, 2011; Lam & Petri, 2005).

A patient's feelings of distress, guilt, and anxiety are due in large part to the negative social experiences they have with individuals who do not understand them and their illness (Brennan & Creaven, 2015; Earnshaw et al., 2012; Sutanto et al., 2013; Hale et al., 2006; Moses,

Wiggers, Nicholas, & Cockburn, 2005; Kozora, Ellison, & West, 2006). Attempts to understand how to improve the lives of patients have begun to move towards assessing the awareness that others, such as medical providers, family and friends and community members have of SLE (Brennan & Creaven, 2015; Hagger & Orbell, 2003; Karlson et al., 2004; Waldron et al., 2011; Young et al., 2002). In order to attempt to improve patients' emotional and physical health new advocacy efforts need to extend to other groups' awareness and knowledge of SLE.

Epidemiology and SLE Disparities

The cause of SLE is attributed to a combination of hormones, genetics, and environmental factors (e.g. ultraviolet rays or various chemical pollutants; Sestak, Nath, Sawalha, & Harley, 2007; Pons-Estel et a., 2010). Twin studies and familial studies have found that SLE is genetic in nature and as many as 100 currently identified genetic risk factors exist that remain latent until an environmental factor triggers onset (Sestak et al., 2007). SLE is disproportionately found in ethnic minority women and individuals of lower socioeconomic statuses (SES; Feldman et al., 2013). Genetic linkages, which are the specific order that genes are expressed on the chromosome, have also been identified within different ethnic groups (Harley, Kelly, & Kaufman, 2006). These linkages have been examined and many are unique to African American patients while other linkages have been identified for European-Americans or Hispanic-Americans (Sestak et al., 2007; Harley, Kelly, & Kaufman, 2006).

It is not clearly understood to what extent environmental factors play a role in the onset of each case of SLE; however, two factors that have been identified as onset triggers are exclusively seen in women: estrogen and the XX chromosome (Crampton, Morawski, & Bolland, 2014). The overall diagnosis rate of SLE in women is 90%, where women are diagnosed nine times more often than men (Bensler & Silverman, 2007). Poverty and

disadvantages in one's environment also plays a direct role in the survival rate of people with SLE (Durán, Apte, & Alarcón, 2007). A vast amount of scientific evidence has identified that the dominant group most commonly diagnosed with SLE are women of minority status in low SES environments (Marengo et al., 2012).

Another disparity that exists for women is being of child-bearing age, which is considered to be between 15 and 45 years-old (Pons-Estel et al., 2010). Women with SLE who are pregnant or attempting to get pregnant are considered high risk due to the heightened risk of first and second-trimester premature births, low birth weights, and fetal deaths (NIAMS, 2006; Clowse, Magder, Witter, & Petri, 2005). Provided that women of childbearing age are at heightened risk of SLE onset, attempts to decrease the adverse effects for the baby and the mother's health during pregnancy have been made. Medications are monitored more closely because some are not safe during pregnancy, which means women are taken off medications that manage their SLE (Clowse et al., 2005). Without these critical medications, disease activity increases. Increased disease activity during a pregnancy is one of the highest risk factors for infant mortality (Clowse et al., 2005). A delicate balance must be kept between medication management, disease activity, and monitoring a fetus' and a mother's health during pregnancy.

Over the last 50 years, improvements in medical care have led to increased availability of medications, the creation of new medications, and new research. All of these advancements have helped to improve the life expectancy of SLE patients. In the 1950's, approximately 50% of SLE patients died within 4 years of symptom expression and today survival rates are higher than 90% after 5 years (Pons-Estel et al., 2010; Harley, Kelly, & Kaufman, 2006). However, patients still suffer long-term decreases in QoL and increased medical costs (Pons-Estel et al., 2010). Even though medical advances have improved survival rates the disproportion of SLE diagnoses in

low SES and ethnic minority patients are still astronomical compared to non-white patients (Williams, Kamen, Penfield, & Oates, 2014). Therefore, increasing the awareness that patients and providers have for higher risk groups could improve the rates of accurate SLE diagnosis.

SLE Education and Interventions

As researchers learn more about SLE and the way that it impacts patients' lives they have created various patient education programs (Cunningham & Kashikar-Zuck, 2013; Brown et al., 2012; Ramos-Remus, Salcedo-Rocha, Prieto-Parra, & Galvan-Villegas, 2000). There have been two attempts at educating patients about SLE disease knowledge (Konttinen et al., 1991; Young et al., 2002). The researchers of these studies implemented and assessed the success rate of patient-specific education programs by providing patients with an educational resource (e.g. internet education website or patient education pamphlets). However, only two specific assessments have examined knowledge education with patients and there have been no attempts to examine the level of knowledge that medical providers, social supports or the general public have of SLE. The lack of attention given to knowledge levels for these other groups leaves a gap regarding ways to improve the lives of patients by increasing awareness of SLE.

The first attempt to assess patient knowledge of SLE was in 1991 when Konttinen and colleagues provided SLE patients with a patient education guide and assessed pre- and post-test knowledge. Researchers created a patient guidebook that incorporated SLE disease information and positive coping mechanisms for patients. The researcher's primary aim was to assess whether having access to a medically accurate SLE source would produce significant improvements in patient knowledge of their disease. The second aim was to examine whether being informed about positive coping behaviors would improve psychological well-being. Researchers concluded that psychological functioning did not change, but patients' knowledge of

SLE did significantly increase over the course of the 8 to 10 weeks that knowledge was assessed. Konttinen and colleagues (1991) concluded that the improvement that their participants indicated that patients were interested in learning more about their disease and that learning more about their disease was beneficial for patients.

Another attempt to test patients' knowledge utilized an internet based information center for patients called LupusHelp (Young et al., 2002). The goal was to increase patient knowledge and researchers wanted to determine if having free online access to pamphlets, videos, and support groups related to SLE could further increase patients' knowledge. Patients who completed the pre- and post-test knowledge test showed significantly improved knowledge. Indicating that for those who visited this LupusHelp web page and completed both the pre-and post- tests gained valuable knowledge of SLE. Although patients' knowledge and well-being improved the researchers did not extend the benefits of this remote resource to other groups like the general public, medical providers, and social supporters.

Psychological treatments and therapy options have developed and utilized a more collaborative technique for including disease education into treatments. Psychoeducation is the educational component in therapy that involves explaining to the client how treatment will specifically help their mental health concerns; however, when a patient has a comorbid physical condition the psychoeducation also includes specific disease information (Keefe, 1996). One way that psychoeducation is implemented is within the goals of Cognitive-Behavioral Therapy (CBT) methods (Keefe, 1996; Keefe, Somers, & Martire, 2008; Evers, Karrimaat, Van Riel, & De Jong, 2002). CBT treatment modules have been created to target the experience of pain associated rheumatologic conditions (Sharpe, 2003; Haupt et al., 2005). Clinicians use treatment goals to educate patients on how their disease can be managed and to teach skills specific to the

symptoms related to SLE (Rinaldi et al., 2006; Haupt et al., 2005). Evidence suggests that educating patients about their disease in therapy is related to improved health outcomes (Rinaldi et al., 2006; Thumboo & Strand, 2007).

For SLE patients, interventions that incorporate these CBT therapeutic tools and illness-specific information are associated with significant reductions in anxiety, depression, stress and disease activity (Karlson et al., 2004; Zhang, Wei, & Wang, 2012). However, disease education alone is not indicative of significant psychological improvements (Parker et al., 1988; Ottonello, 2007). Ultimately, improvements in QoL occurs when disease knowledge is incorporated into psychological treatments. Although encouraging, this results in a disparity because it implies that only patients receiving psychological treatments are gaining the benefits of these successful results.

The one research design that involved a social supporter or partner into an SLE-specific treatment occurred when Karlson and her colleagues (2004) examined the efficacy of a psychoeducational intervention for SLE patients and had them identify and choose one partner, either a spouse or a family member, to join them in the intervention. The randomly assigned treatment pairs received an intervention designed to increase self-efficacy, communication between the pair about SLE, social support, and problem solving. At the 6-month follow-up, communication and problem-focused coping improved significantly compared to the control group. At the 12-month follow-up, social support, patient self-efficacy, and global mental health of the patient had all improved significantly while fatigue of the patient decreased significantly. However, global physical function of patients and their disease activity, as measured by the systemic lupus activity questionnaire (SLAQ), did not significantly improve over the course of a year. The findings provided evidence of some benefits to having a supporter be a part of an

intervention but that over time a patient's physical functioning may not drastically change. However, the researchers did not incorporate any disease knowledge component to their study. Future studies should incorporate an SLE-specific knowledge questionnaire to assess an additional variable related to dyadic relationships.

Although attempts to educate providers on SLE have not been conducted at this time, researchers have found that patients want their doctors to know more. Waldron and colleagues (2011) conducted interviews with SLE patients and asked them to recall what their information needs were at the time of their diagnosis. The researchers wanted to understand how to improve patients' disease knowledge satisfaction and how to minimize the difficulties associated with information gathering. Patients reported feeling that providers were not as accessible as they wished and that providers did not inform patients of the "full picture" of what SLE is and how it influences life (Waldron et al., 2011). Providers may not be doing all they can to educate newly diagnosed patients. This may suggest that providers are not as competent or confident in their ability to treat and identify SLE. However, conclusions cannot be substantiated due to the lack of information regarding how knowledgeable various medical providers are of SLE. Improved SLE education for medical providers could be a way to counteract the negative experiences that patients report having with their medical providers (Mak et al., 2009).

Common Sense Model of Illness

The Common Sense Model of Illness (CSM) is a theoretical framework that informs patients' experiences living with a chronic illness and how cognitive and emotional factors influence coping behaviors and outcomes (Leventhal, Meyer, & Nerenz, 1980). The model proposes that a patient's perceptions about the illness experience influence the overall illness representation, coping strategies, and future health outcomes. Patients' perception their illness

and whether they employ positive or negative coping strategies has a direct relationship between disease severity and health outcomes (Cameron, 2003).

There are five components that influence how illness perceptions develop: identity, cause, timeline, consequences, and curability/controllability (Hale, Treharne, & Kitan, 2007). The *identity* component labels a condition and the symptoms that are experienced. Having labels allows the patient to be able to identify and continue to re-identify the schematic representation of their disease. Recurrent symptoms strengthen the labels while new symptoms provide more detail regarding the disease. The *cause* component refers to the individualistic ideas about the perceived cause of the condition. The cause can include information gathered from four contexts: the biological cause (immune system), emotional cause (stress), environmental cause (pollution) and psychological cause (personality or mental state; Hagger & Orbell, 2003; Diefenbach & Leventhal, 1996). Information gathered about cause does not necessarily involve factual information regarding the cause; instead, these representations are often based on personal experiences and information gained through the opinions of others. Significant others, medical providers, and the media all influence the individual's belief about what caused their diagnosis.

The *timeline* dimension is the belief about how long the condition may last, understanding if an illness is chronic or acute. As the individual adds new details to their illness representation patients re-evaluate their timeline representation. The *consequence* dimension is the component of the model that addresses beliefs regarding the impact an illness has on a person physically and socially. Only over time does an individual begin to identify accurate beliefs rather than irrational ones (Hale, Treharne, & Kitan, 2007). Theoretically, the longer a patient is diagnosed with a disease his or her understanding of the disease becomes more accurate. Finally, the *curability/controllability* component addresses the beliefs an individual has regarding

whether the condition can be cured and/or controlled (Leventhal, Meyer, & Nerenz, 1980). This involves understandings of treatment options and the effects of treatments (i.e., management vs. curable). Information about each of the five CSM components are continuously collected and evaluated throughout a patient's life. Providing opportunities to give patients accurate SLE information could aid in the process of re-evaluating inaccurate illness representations and create a new more accurate representation based on accurate knowledge.

According to the CSM, information is gathered in three different ways. The first is through *general or layperson information* gained from previous social communication and cultural knowledge of the illness. Therefore, individuals who interact with patients need to be aware and knowledgeable of the disease because illness representations are partially based off the knowledge that individuals around the patient (e.g., community) have of SLE. This means that the general public should understand SLE and how it impacts patients. The second is information gained from *external social environments* from significant others or expert sources (e.g. doctor). This area of information gathering is important because if experts and significant others do not have accurate knowledge of SLE the patient is at an increased risk of being exposed to more misinformation. Accurate transmission of knowledge is critical and those who are close to a patient need to be accurately informed. The final source of information gathering occurs due to the *subjective experience* of a patient's illness. Throughout life the illness representation evolves (Hale, Treharne, & Kitan, 2007; Leventhal, Meyer, & Nerenz, 1980). Patients need to remain informed of their diagnosis and how it will affect them.

An individual creates a mental representation of his or her illness using concrete and abstract information that is gathered throughout the course of the illness. This information is then associated with the overall disease experience; this linking of information to the individual's

illness representation is automatic and intrusive (Hagger & Orbell, 2003). As a person experiences more intensified symptoms he or she appraises the information gathered to determine the level of threat perceived about the illness based on current symptoms. The appraisal cycle is what leads to the construction of an illness representation. For example, when presenting symptoms activate a negative emotional response (i.e. fear, sadness, worry) the symptoms and the association with negativity strengthen the representation that the symptom is more dangerous (Cameron, 2003). Ultimately, the more intense an illness is and the more symptoms experienced, the more likely a patient is to increase the subjective association of the illness being dangerous. If patients believe they have coping skills to combat their negative experience, then they can employ these skills. If patients do not believe they have the appropriate coping skills, they remain in a high level of distress.

The CSM theorizes how individuals identify and process information regarding their illness, how that information is integrated to provide a representation of their illness, and how to employ appropriate coping behaviors (Hagger & Orbell, 2003). As someone obtains new information about his or her condition he or she reevaluate their illness representation. By improving accurate SLE disease knowledge patients can work to reframe their illness representation (Cameron, 2003). Improving the awareness and accurate knowledge of SLE among the general public, medical providers and social supporters could be a way to interrupt false information transmission to the patient. The more accurate and realistic an illness representation is the more likely patients are to utilize appropriate coping behaviors for managing SLE (e.g. seeking medical care, avoiding risky behaviors), which improves disease experience and QoL. Therefore, it is important for a patient's illness representation to be informed by accurate knowledge.

Implications for Knowledge Assessment in SLE

Having a rare chronic illness has a large impact on a patient's life. By having an accurate understanding and awareness of physical and psychological symptoms of SLE patients' illness experiences could be improved. Increasing knowledge is a way to raise awareness and combat negative disease experiences; therefore, assessing SLE knowledge can have implications for helping patients, medical providers, and supporters of patients (Hale et al., 2006). The next subheadings address why the assessment of accurate SLE knowledge is important.

Physical Complications. People living with SLE experience a multitude of physical symptoms, including but not limited to, inflammation, joint pain, fatigue, skin rashes, and severe deterioration of one or several organ systems (Sutanto et al., 2013). Fatigue is most persistent and often results in low muscle strength, which is a concern in SLE patients because the muscles and joints are at increased risk of deterioration (Parrondo, 2011). Symptoms of SLE do not occur independently; rather, they occur together and exacerbate each other. This interaction between physical symptoms and the disease progression is important to understand because symptom flares vary in severity. Is important for patients to be aware of their limitations when flares are severe because disease activity is one of the most predictive factors of patients' health status (Dobkin et al.,1999; Rinaldi et al., 2006).

The complexity of SLE often leads to a lengthy and daunting diagnostic process. Diagnosing SLE requires upwards of 20 tests used in combination and it is common to take up to 5 or more years to receive a diagnosis (Lam & Petri, 2005; NIAMS, 2008). The American College of Rheumatology developed the 11 diagnostic criteria for diagnosing SLE (Hochberg, 1997). The individual must exhibit at least four criteria, at least one medical test confirmation and one affected organ system. The diagnostic categories include rashes (malar or discord),

photosensitivity, mouth sores, arthritic symptoms, lung/heart inflammation, renal disorder, neurological disorder, hematologic disorder, immunological disorder, and a positive Antinuclear Antibody (ANA) test. There is no cure for SLE and the progressive style of disease activity is serious. The longer patients go without receiving a diagnosis, the longer they go without the appropriate treatments (Lau & Mak, 2009). Improving knowledge of SLE symptoms among those at higher risk for SLE could lead to an earlier diagnosis because individuals could identify symptoms earlier and see out the appropriate care. Additionally, improving medical providers' knowledge of SLE symptoms could lead to an earlier diagnosis window for future patients because they would be aware of the combination of symptoms that constitute an SLE diagnosis.

SLE is referred to as "the great imitator" because of the way that symptoms mimic a variety of other chronic illnesses, such as rheumatoid arthritis, fibromyalgia, hypothyroidism, multiple sclerosis, and more general dermatology disorders, endocrine system dysfunctions, and infections (Sutanto et al., 2013; Benseler & Silverman, 2007; NIAMS, 2008; Cojocaru, Cojocaru, Silosi, & Vrabie, 2001). It is critical for patients to know that as their overactive immune system continues to attacks various healthy organ systems they are at an increased risk of a variety of additional life-threatening comorbid diseases (Pons-Estel et al., 2010). People living with SLE are at increased risk for pulmonary, cardiac, gastrointestinal, ocular, hematologic and neuropsychiatric disorders (Parrondo, 2011). The physical complications of SLE go through ebbs and flows and the risk of comorbid diseases is high. Being aware of the complications that symptoms present is important to help patients manage their SLE daily.

Psychological Complications. Danoff-Burg and Friedberg (2009) assessed the satisfaction of patients' needs and found that 91% of their SLE sample reported a psychological need being unmet. Not only do patients' needs remain unmet, but they also experience a general

negative affect and are more susceptible to psychological distress, such as additional stress and worry (Moses, Wiggers, Nicholas, & Cockburn, 2005). The increase of distress and dissatisfaction lead individuals to be at an increased risk of more severe mental health concerns, which, in turn, exacerbate disease activity. Nery and colleagues (2007) reported that life events contribute to the onset, recurrence, and severity of depression and that overall psychological distress is associated with life events. For example, when life events related to an SLE diagnosis are perceived as negative or stressful a patient's life satisfaction and report of quality of life decrease (Bennett, Fuertes, Keitel, & Phillips, 2011; Earnshaw, Quinn, & Park, 2012). The nature of SLE continues to influence the mental health of patients far beyond the diagnosis.

Comorbid psychological disorders occur more often in SLE patients compared to the general public. Mood disorders such as major depressive disorder (MDD; single episode and recurrent episodes), depression due to a general medical condition, and depressive episodes not otherwise specified (NOS) have been reported in up to 69% of SLE patients (Nery et al., 2008). MDD, is in fact, the most diagnosed disorder for patients with SLE; the lifetime prevalence rate has been estimated to be 49.2% (Kozora, Ellison, & West, 2006; Nery et al., 2008; Stojanovich, Zandman-Goddard, Pavlovich, & Sikanich, 2007; Julian et al., 2009; Nery et al., 2007). However, the national average for receiving an MDD diagnosis in life is only 20.8% (Kessler et al., 2005). Unfortunately, providers and patients often times attribute depressive feelings to a general low mood and do not take the necessary precautions to help manage the true severity of depression (Giffords, 2003).

Disease activity has a direct relationship to psychological symptoms because as a patient's disease severity increases their reports of anxiety symptoms increase as well (Bachen, Chesney, & Criswell, 2009). Anxiety is another common psychological concern for SLE

patients, with a lifetime prevalence rate being as high as 52% (Meszaros, Perl, & Faraone, 2012; Bachen et al., 2009; Nery et al., 2008; Stojanovich et al., 2007; Beckerman et al., 2011). However, lifetime prevalence of anxiety disorders in the general population is lower at 28.8% (Kessler et al., 2005). In a large all female sample only 4.3% of the sample met diagnostic criteria for generalized anxiety disorder (GAD) at the time of the study (Bachen et al., 2009). Many factors go into having a current GAD diagnosis and just because someone does not meet the necessary criteria to receive a formal diagnosis does not mean the level of worry and anxious feelings experienced do not negatively impact the patients' life. Instead, some level of anxiety related diagnosis is experienced at a relatively high rate. Anxiety-related disorders such as specific phobia (24%), panic disorder (16%), and obsessive-compulsive disorder (9%) were also diagnosed in SLE patients at a significantly higher rate than the general population sample (Bachen et al., 2009). Although the specific diagnosis may vary across patients, the rate of anxiety and anxiety-related disorders is severely elevated in this disease population.

Psychosis is also a serious concern for SLE patients. It is diagnosed in 2-3% of SLE patients but as high as 31-39% for those on high doses of corticosteroids (Pego-Reigosa & Isenberg, 2008). Long-term corticosteroid medication use has adverse effects on hippocampus receptors which have been found to directly cause hallucinations and paranoia (Nery et al., 2008; Mak et al., 2009). Corticosteroids are one of the more dangerous treatment medications that are used intermediately for patients throughout the course of their life. Due to the high toxicity, the recommendation is that any steroid medication should be used in the lowest dose possible, for the shortest amount of time that results in disease management (Chatham & Kimberly, 2001). Corticosteroids minimize the progression of autoantibodies that attack the healthy cells and decrease inflammation; therefore, patients who experience more severe flares, cutaneous skin

lesions, advanced SLE lung disease, renal disease, and severe inflammation are prescribed steroid medications (Chatham & Kimberly, 2001). Even though providers should only prescribe corticosteroids in small doses, some patients are prescribed them for substantially longer periods of time, which increases patients' susceptibility to additional medical conditions and increased psychological concerns (Chatham & Kimberly, 2001; Pego-Reigosa & Isenberg, 2008).

Quality of Life. Quality of life (QoL) has been identified as an indicator of the health status in patients with chronic diseases (Freire et al., 2011). In general, patients with SLE report decreased satisfaction with their lives due to their physical and mental health concerns. Those with more severe SLE report worsened physical health and have decreased social interactions, which leads to less supportive relationships (Panopalis & Clarke, 2006; Dobkin et al., 1999). Patients variability in their physical (e.g. increased symptom severity/flares), mental (e.g. general low affect and psychiatric disorders), and social (e.g. relationships with physicians) experiences place these patients at increase susceptibility of lower QoL. Compared to the average American adult, SLE patients are functioning at a lower level than non-diagnosed individuals (Pons-Estel et al., 2010). For individuals living with chronic illness, QoL is critical. Their life is often interrupted by their disease. For patients living with SLE, their experiences are so unique that they are susceptible to additional factors that threaten their QoL (Yazdany, 2011). Factors influencing SLE-QoL, include age, duration of illness, amount of education, self-efficacy, knowledge of lupus, and social support (Thumboo & Strand, 2007; McElhone et al., 2007).

Stigmatization. The invisibility of SLE increases patients' daily stress level because they can experience isolation and stigmatization from the public, medical providers, and even their social support networks (Hale et al., 2006; Kool & Greene, 2012; Kool et al., 2010). Feelings of anticipated stigma, fears of rejection, increased self-consciousness, and reports of guilt regarding

their diagnosis are common for someone living with SLE (Earnshaw et al., 2012; Sutanto et al., 2013). Patients' experiences with negative social interactions increase their stress levels and lead to perceptions of less support. Patients report that when individuals such as friends, family, and work colleagues do not fully understand their disease they feel stigmatized for their experiences, which perpetuates their distress (Hale et al., 2006; Earnshaw et al., 2012). Feeling misunderstood causes more distress and is associated with decreased mental and physical health of SLE patients (Dobkin, et al., 1998).

Another source of increased worry that patients feel is related to the self-conscious feelings experienced when visiting physicians (Beckerman et al., 2011). Patients have reported that they worry about physicians judging them during their medical appointments and these worries increase when patients believe their doctors perceive them as uneducated. SLE is diagnosed more in individuals who are from lower SES populations and this increased distress of stigmatization because of low education has a major impact on patients' perceptions of themselves. This stigma worry is an additional barrier for SLE patients when it comes to seeking appropriate medical care (Feldman et al., 2013). Patients express concern that they do not want to look bad in front of their health care professionals and if they perceive their provider is likely to stigmatize them, they are likely to avoid going.

Medication Adherence. When SLE is not managed properly, disease activity and complications increase (Lau & Mak, 2009). Medication use is the most common treatment for SLE because of the direct biological influence. Medication non-adherence is also a contributor to the increased health care cost of SLE (Lau & Mak, 2009). As disease activity increases so does the cost of care for an individual with SLE, this often relates to the necessary hospitalization stays that are often required when disease activity is severe (Holloway et al., 2014). Non-

adherence rates in patients are as high as 76% which can be extremely dangerous for a patient's life, both physically and mentally (Costedoat-Chalumeau et al., 2013).

Patient's knowledge of treatment options and his or her belief of the necessity for correct adherence has also been associated with higher non-adherence rates (Costedoat-Chalumeau et al., 2013; Chambers, Raine, Rahman, & Isenberg, 2009). Increased psychological distress, most specifically depression, also threatens the consistency and accuracy of medication adherence (Marengo et al., 2012; Coleman et al., 2012). Since SLE patients are at higher risk for depression, they are inherently more susceptible to poor medication adherence (Julian et al., 2009). Additionally, just as patients sometimes avoid doctor appointments when they feel that their physician judges them, poor rapport with a provider also plays a role in the individual's non-adherence. If a patient feels unheard and disregarded by their provider, they are less likely to inform their physicians of new or worsening symptoms (Sutanto et al., 2013). Increased rates of psychological distress, poor physician relationships and a lack of information regarding the importance of accurate medication use all can contribute to poor medication adherence.

Benefits of Disease-Specific Questionnaires

Previous researchers have explored the importance of assessing specific disease knowledge. Through more focused assessments of disease knowledge researchers are better able to understand levels of knowledge among various groups. Specifically, these research designs provide opportunities to assess what knowledge patients do or do not have, what medical providers know and where gaps of knowledge exist, and assess the level of knowledge that family and friends and the general public have of the disease. Further examination of disease knowledge could be a way to increase knowledge and awareness of SLE while concurrently decreasing stigmatization. Since no SLE-specific knowledge questionnaire exists, understanding

how other disease-specific knowledge questionnaires have been designed and implemented is informative to understand the process that developing an SLE-specific questionnaire would take.

Carpenter and colleagues (2009) created a new and valid general knowledge questionnaire to assess Alzheimer's disease (AD) knowledge. They developed a pool of questions that were previously used in other measures to assess AD knowledge within patient, professional, and community samples. This provided the researchers the opportunity to gather a wide range of items for the new questionnaire, which consisted of questions targeting risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving and treatment. The final product consisted of true/false items that allowed for a short and quick questionnaire. Knowledge was significantly higher for those who had attended a support group for dementia and for those who worked with patients with dementia than those who had not, those who were college students or those who worked in a senior center (Carpenter, Balsis, Otilngam, Hanson, & Gatz, 2009). Findings suggest that there are group differences in disease knowledge given an individual's awareness of AD. Specifically, the more personal experience and awareness that participants had was reflected in their AD knowledge.

Another example of assessing disease-specific knowledge is for diabetes-specific knowledge questionnaires. Multiple diabetes knowledge questionnaires have been developed and tested. Fitzgerald and colleagues (1998) examined the reliability and validity of a brief diabetes knowledge test while other researchers have created and examined alternative measurement tools (e.g. Revised Diabetes Knowledge scale; Collins, Mughal, Barnett, Fitgerald, & Lloyd, 2010). Fitzgerald and colleagues (1998) compared patient scores that were collected from two different medical centers. They determined that there were differences among scores depending on the medical setting and patient populations and there was a degree of variability between groups.

Collins et al. (2010) additionally compared the effects that different response formats could have on scores. The new measure was adapted to have binary responses based on the multiple-choice items found on the Simplified Diabetes Knowledge Scale. Results indicated that average scores were remarkably similar (62% (multiple choice) compared to 65% (true/false)). The responses style does not seem to affect the outcomes when it comes to testing disease-specific knowledge.

Many other disease-specific knowledge questionnaires exist, including ones assessing STD and HIV knowledge (Carey & Schroder, 2002), heart disease (Bergman, Reeve, Moser, Scholl, & Klein, 2011; Wagner, Lacey, Chyun, & Abbott, 2005), chronic obstructive pulmonary disease (OCPD; White, Walker, Roberts, Kalisky, & White, 2006), cystic fibrosis (Siklosi, Gallagher, & McKone, 2010), multiple sclerosis (Giordano et al., 2010), fibromyalgia (Suda, Jennings, Bueno, & Natour, 2012), osteoporosis (Winzenberg, Oldenburg, Frendin, & Jones, 2003) and arthritis (Edworthy, Devins, & Watson, 1995). Researchers have also conducted studies to examine the level of knowledge that different groups have. Disease-specific knowledge questionnaires have been used in various disease populations and have been used in conjunction with additional educational intervention material to improve the awareness that patient populations and significant others have of various diseases.

Purpose of Proposed Study

Assessing SLE-knowledge could provide increasingly important benefits to a variety of groups by working to reframe the social perspective that others have on this complex invisible disease. Creating additional educational material that could be used to improve the knowledge that community members have of SLE might help raise awareness of the disease and decrease SLE stigma. Improving patients' knowledge of SLE might encourage them to take a more active role in disease management by being aware of disease outcomes. Increasing the knowledge that

medical providers have of SLE could help speed up the diagnosis process and improve patients' outcomes. Decreasing the stigmatizing misconceptions of SLE could further improve patients' relations with family, friends and employers. Together, increasing knowledge about SLE could help facilitate increased awareness, reductions in stigmatization, and improved patient outcomes.

Assessing SLE knowledge in a community sample is the first step in an overall research agenda to understand what the level of accurate knowledge and awareness is of SLE. This is the first study of its kind to create an SLE-specific knowledge measurement tool in order to assess general knowledge of SLE in a community sample. It is the aim of the following proposal to develop the first SLE specific knowledge questionnaire and use the questionnaire to explore SLE knowledge and the influence of educational exposure and disease proximity. This study involves the following research questions and hypotheses:

RQ1) What are the common topics that providers identified as being important to be included in the Lupus Knowledge Questionnaire?

RQ2) How do participants in a community sample score on the LKQ?

H1) Individuals with educational exposure of SLE will have higher scores on the LKQ than those who have no previous educational exposure to SLE.

H2) Individuals who have closer disease proximity to SLE will have higher scores on the LKQ than those who know no one with SLE.

Method

The current study occurred in four phases guided by adaptations from the questionnaire development protocol created by the European Organization for Research and Treatment of Cancer (EORTC; Johnson et al., 2011). The protocol had been previously adapted and used by researchers to create disease knowledge questionnaires (Jaglarz, Tomaszewski, Kamzol, Puskulluoglu, & Krzemieniecki, 2014), quality of life measures (Wheelwright et al., 2013), and patient outcome measures (Denniston, Kyte, Calvert, & Burr, 2014; Reeve et al., 2013).

Phase 1 consisted of interviews with medical experts. Phase 2 incorporated drafting a version of the lupus knowledge questionnaire (LKQ); items were created by utilizing qualitative methods to analyze interview responses and conducting a thorough literature review of educational material used by the Lupus Foundation of American to inform individuals about SLE. Phase 3 consisted of the draft version being reviewed for relevance, accuracy, and clarity by the same experts who were interviewed during Phase 1. Edits to the LKQ were made based on results from a regression analysis and feedback from the providers. Phase 4 concluded the proposed study and consisted of two administrations of the LKQ. The first sample was given the draft version of the LKQ and a unique second community samples was administered the revised version of the LKQ. The samples were used to gather initial psychometric data: internal consistency, item analyses (item difficulty/discrimination, readability) and data on participants' LKQ scores. Institutional Review Board approval was obtained from the university to conduct all aspects of this study.

Phase 1: Conducting Provider Interviews

Participants. Three medical providers (2=MDs; 1= Nurse Practitioner) were recruited to consult as experts. Two of the providers were male and one provider was female. Previous

researchers recommend using a minimum of two experts to act as consultants to gather knowledge data; therefore, the use of three experts was considered adequate (Siklosi et al., 2010; White et al., 2006; Jaglarz et al., 2014). In order to participate in the study, the providers needed to have previous experience diagnosing, treating and caring for SLE patients. The medical providers were recruited from medical centers in Indiana through existing personal and professional relationships.

Procedure. To address Research Question #1, medical providers were asked to complete a one-on-one interview to gather qualitative data of relevant SLE knowledge topics. The interview protocol was informed by the dimensions of the Common Sense Model of Illness because of the focus on disease experience and representation. Interviews are commonly used methods used to collect content related to a topic (Gill, Stewart, Treasure, & Chadwick, 2008).

Measures and Materials. Materials included a hand held recording device and the interview protocol. Responses to the interview were recorded to allow for easy reexamination of the interview content. Interviews were conducted over the phone and experts were first asked to consent to the study before completing the interview. Questions in the semi-structured interview protocol included, *what resources do you have at your disposal to assist you in providing education/knowledge to your SLE patients, what questions regarding SLE do patients not ask about that they should, and what should people know about SLE to have a good general understanding of the illness and how it is experienced by people?* (See Appendix A for Full Interview Protocol.)

Phase 2: Reviewing Patient Education and Interview Data

Procedure. Previous researches who have created disease-specific knowledge questionnaires begin by gathering or adapting a pool of items from previously validated studies

that assessed the disease in question (Davis, 1992; Giordano et al., 2010; Carpenter et al., 2009; Siklosi et al., 2010). Alternatively, researchers gather general information regarding accurate disease information from both literature and expert individuals (e.g., physicians, psychologists, nurses, nutritionists; Siklosi et al., 2010; White et al., 2006; Wagner et al., 2005). Given that the LKQ is the first of its kind, there were no existing questionnaires to assess. Therefore, only the latter method of item creation was used in the current study.

First, I conducted a literature review to gather information regarding educational information on SLE. Secondly, I used the medical providers' interviews to guide item creation. Finally, I assessed materials used by the Lupus Foundation of American to inform patients, social supporters, medical providers and the general public regarding SLE.

A true and false response format with a "don't know" option was utilized for the LKQ; this was a commonly endorsed response style used to develop disease knowledge questionnaires (Carpenter et al., 2009; Edworthy, Devins, & Watson, 1995). This option allowed for easier administration and more accurate representation of factual knowledge, as compared to a multiple-choice design, which is more beneficial for attitude questions (Beatty & Herrmann, 1995; Poe, Seeman, McLaughlin, Mehl, & Dietz, 1988). When a "don't know" option does not exist participants have reported feeling more compelled to respond without having any basis for their answer, resulting in incorrect representations of knowledge. Additionally, including the "don't know" option allowed identification of items that resulted in higher awareness versus lower awareness.

Materials. I used the content from the interviews to inform the initial content of the items. Additional support, in terms of wording or more specific details, was gathered through the examination of pamphlets developed by the Lupus Foundation of America to educate

individuals. Therefore, the materials used to inform the items remained the interviews and the pamphlets from the LFA.

Analyses. Qualitative content methods were used to inform the collection of items on the LKQ. I developed a pool of items based off information gathered from the interviews and the pamphlet content. Components of directed content analysis as well as standard disease-specific knowledge questionnaire methods were utilized to determine the content of the LKQ items. Aspects of a directed content analysis were applied because of this method's focus on being informed by an existing theory (Hsieh & Shannon, 2006). Items focused on general knowledge of SLE rather than very nuanced aspects of the SLE-disease experience (Johnson et al., 2011; Jaglarz et al., 2014; White et al., 2006; Hennell, Brownsell, & Dawson, 2004, & Holloway et al., 2014). The CSM's dimensions (identity, cause, time-line, consequences, and curability/ controllability) were used to inform the interview questions and items' final content (Hagger & Orbell, 2003; Hale, Treharne, & Kitas, 2007; Potter & Levine-Donnerstein, 1999).

The initial step of item creation occurred by assessing the broad content areas that the providers reported as being important through the interviews. After that, the broad themes were described and elaborated on by compiling all the interviewers' interviews. After this broad step was taken the pamphlets were utilized to gather more specific factual information based on the providers' answers. The pamphlets allowed for me to fill in gaps from the interviews. For example, the item related to skin rashes was discussed by all three providers and it was covered in the pamphlets. Therefore, that item was unanimously supported. Another example is with the item that asked if SLE is called *the great imitator*. For this item, the providers broadly spoke of SLE as being difficult to diagnose because it mimics other conditions. However, the pamphlets specifically used this verbiage; thus, the pamphlet was used to create the specific item content.

Phase 3: Verifying and Revising LKQ Draft

Participants. The same medical providers from Phase 1 reviewed the LKQ-draft version and provided feedback on the relevance of the items as well as provided suggestions on item clarity and/or accuracy. Utilizing experts to inform and review disease specific questionnaire is commonly used to confirm the content validity of a measure (Johnson et al., 2011; Jaglarz et al., 2014; White et al., 2006; Hennell, Brownsell, & Dawson, 2004, & Holloway et al., 2014).

Procedure. Verification and content validity was assessed by having the medical providers complete the Content Validity Index (CVI; Beck & Gable, 2001; Polit & Beck, 2006). The providers were sent the draft version of the LKQ along with the CVI to rate each item on relevance and accuracy. After the providers rated the content and provided feedback, appropriate changes were made. For example, if providers gave an item a score of 1 or 2 (see below) and provided feedback for the item, that feedback was incorporated and the item was changed to make it a highly relevant item. The editing involved correcting the wording of the item and increasing clarity of the items based on the additional feedback that the providers left. If an item was not considered relevant the providers were asked to give feedback that they believed would make that item highly relevant. After all of the providers' feedback was incorporated the revised version was generated. (See Appendix B for the Provider Verification Documents.)

Measures. The following measures were given to the three medical providers and data were used to inform any changes that took place when creating the revised version of the LKQ.

Content Validity Index Scale. The Content Validity Index Scale (CVI) is a method of quantifying content validity based on expert ratings (Polit & Beck, 2006). On the CVI, the providers were asked to give feedback on item relevance on a 4 point Likert-type scale (1 = *not*

relevant, 2 = *somewhat relevant*, 3 = *quite relevant*, 4 = *highly relevant)* and provide feedback regarding the accuracy and clarity of the medical facts represented in the items.

Analyses. Scores were calculated based off the CVI procedure. A CVI value was computed for each item on the scale (I-CVI). Among the literature there was a lack of clarity regarding the specific method that researchers have used to assess each item's content value (Lynn, 1986; Polit & Beck, 2006). For the current study, the method used to calculate the I-CVI was conducted by having the relevance scores of each item tabulated into not relevant (ratings of 1 and 2) and relevant (ratings of 3 or 4). The I-CVI was then computed by summing the three scores that each item was awarded and then it was divided by the number of experts (Polit & Beck, 2006). However, if a provider gave written clarity or accuracy feedback those edits were made and then the item was considered a 4 so that score overrode the score of one or two. (See Appendix D for CVI verification feedback)

Lupus Knowledge Questionnaire-Draft (LKQ). The draft version of the LKQ was sent to the providers and consisted of 38 items related to central domains of SLE knowledge. The items were informed by the theoretical framework outlined by the CSM and the item content was gathered from a literature review of patient education material and medical provider interviews. Items were created with a True/False and "don't know" structure. Each item was assessed by the three medical providers. (See Appendix E for the LKQ items in the CSM dimensions.)

Phase 4: Testing the LKQ and the LKQ-R

Participants. The final phase of the current study consisted of two full-scale administrations of the LKQ. The draft-LKQ was first distributed to a sample size of 336 participants. Of those, 192 identified as female (57.1%) and the majority of the sample identified as Caucasian/White (N = 278; 82.7%). The mean age was 21.5 (SD=1.82) with ages ranging

from 18 to 24 years old. Just over half of the sample was enrolled in college in some capacity, part-time (N=21; 6.3%) or full-time (N=165; 49.1%; Table 1: Frequency of Demographic Variables).

The LKQ-R was distributed to a second independent community sample of 241 participants. There were a total of 237 participants who participated in the second administration of the revised LKQ. However, fewer participants' data were used for the final analyses. One of the many edits made to the LKQ-R was to include a validity item (item 20: Please answer "true" for this item). After initial demographic data were collected and analyzed 49 participants incorrectly answered the validity question by choosing doesn't know rather than true. Therefore, those 49 individuals' data were excluded from the remaining analyses. Additionally, four individuals did not provide an answer at all. In order to treat the validity item as intended, these four individuals were also excluded. The final sample size for the second administration was 188 participants.

Of the included participants, the majority were female (N=144, 76.7%). The average age of the participants was 33 (SD=6.11) and ages ranged from 20 to 54 years old. Most of the sample identified as Caucasian/White (N = 154; 83.2%) and followed by African American (N=10, 5.4%). Approximately ¾ of the participants were married (N=173, 73.3%). The Average years of education was 15.6 (SD=2.24; see table 8 for Frequency of Demographic Variables).

Procedure. The same procedure was used to recruit participants from both community samples. Participants were recruited by students who were enrolled in a combined undergraduate and graduate psychology course to participate in an online survey through surveymonkey.com. As a course requirement, students had to recruit participants through the use of a snowball sampling method such that each study approached at least one possible participant and asked that

participant to identify at least one more potential participants and so on (Patton, 1990). Students in an advanced psychology laboratory class recruited eight English-speaking community members to complete the online survey. All students involved in data collection were required to complete training in the ethical conduct of research and alternative assignments were provided to reduce the likelihood of data fabrication. Parents provided informed consent prior to completing the full survey. The first sample consisted of young adults and they had to be between age 18 to 24. The second sample consisted of adults who had to be a parent. Class research credit was given to the students for recruiting effort and students were not penalized for failing to recruit the required number of participants. The participants completed a battery of questionnaires aside from the current studies' measures. The data collected for the current study were collected as part of a larger data collection project; thus, other studies' data were collected concurrently. For this study the data gathered from both samples included informed consent, demographic survey items, perceptions of knowledge items, disease proximity and educational exposure items, and the appropriate LKQ version.

Measures. Participants from both samples were asked to complete the following measures. The first sample completed the draft version of the LKQ and the second sample completed the revised version of the LKQ:

Demographics. The items included asked participants about their age, race/ ethnicity, level of education, and marital status. *(*See Appendix C for Demographic Questions.)

Disease Proximity to SLE. Participants were asked to indicate their relation to SLE based on four yes/no items meant to assess disease proximity. The disease proximity items were used to determine whether the individual had close proximity to SLE due to personally being diagnosed with SLE, having immediate family members diagnosed, extended family family

diagnosed, or if they knew anyone else with SLE. Participants were offered the option to skip the disease proximity items with the assurance that they would not be penalized. If participants answered "yes" to having known a family member (immediate or extended) or another person with SLE they were also asked to provide a description of their relation to the participant (ex. Cousin, friend, co-worker; See Appendix C for Disease Proximity Items).

For the purposes of analysis, due to the overlap of endorsed proximity, I had to categorize the groups as the following: group 1 consisted of people who reported having personal SLE and/or knew a family member (immediate and/or extended) with SLE; group 2 consisted of participants who indicated knowing someone else with SLE; group 3 consisted of people who reported having none of the above proximities to SLE. Due to the low number of individuals who reported personally having SLE or reported having a family member diagnosed with SLE, those individuals who did endorse that item were automatically placed into group 1. This occurred regardless of any additional endorsement of knowing someone else with SLE. Those individuals who were in group 2, only endorsed knowing someone else. Therefore, having a closer proximity meant a participant's data were used within that closer proximity group.

Educational Exposure to SLE. Participants were also asked to indicate their educational exposure to SLE based on four yes/no items meant to assess their exposure to SLE-disease information that they gathered through a learning related environment. The educational exposure items included questions related to whether the participant had heard of SLE, had they attended a lecture on SLE, had they learned about SLE in a class, and had they read about SLE. (See Appendix C for Educational Exposure Items).

For the purposes of analysis, to determine groups for the educational exposure groups participants were similarly imposed into the various groups. I had to categorize the groups as the

following: group 1 consisted of people who reported having heard of SLE; group 2 consisted of participants who indicated having read about SLE, learning about SLE in a class, and/or attending a lecture on SLE; group 3 consisted of people who reported having none of the above exposures to SLE. Due to the low number of individuals who reported having a deeper educational exposure to SLE, those individuals who did endorse that item were automatically placed into group 2. This occurred regardless of any additional endorsement of hearing about SLE. Those individuals who were in group 1, only endorsed having heard of SLE. Therefore, having a deeper educational experience meant a participant's data were used within that deeper educational group.

Perception of Knowledge. Participants were asked to rate their perceived level of knowledge before and after taking the knowledge questionnaire. Prior to the participants completing the LKQ they were asked to rate how confident they were about their knowledge of SLE (1= *Not Confident*, 5= *Extremely Confident*). After participants completed the LKQ they were asked to report their perceived score on the LKQ (0-100%) as well as how well they perceived their knowledge of lupus to compare to the average person (1= *I have more knowledge than the average person*, 5= *I know nothing compared to the average person*; See Appendix C).

Lupus Knowledge Questionnaire-Draft (LKQ). The draft version of the LKQ that was administered to the first community sample consisted of 38 items related to the central domains of lupus knowledge identified during the phases of questionnaire development. Items were created with a True/False and "don't know" structure (see Appendix F for Draft Version).

Lupus Knowledge Questionnaire-Revised (LKQ-R). The revised version of the LKQ was created after data was gathered from the initial sample of participants and the CVI feedback was incorporated. The edited version consisted of 34 items related to the central domains of

lupus knowledge identified during the phases of questionnaire development. Items remained in the True/False and "don't know" structure. The LKQ-R was used in the second administration of Phase 4 (see Appendix G for Revised Version).

Analyses. The same analyses were conducted for both samples, except that item discrimination was also conducted for the second sample. Participants completed the survey through an online link and following data collection all responses were entered and analyzed in the Statistical Package for the Social Science (SPSS) version 19 software (IBM Corp., 2010). Descriptive statistics including frequencies, percentages, and measures of central tendencies were calculated for survey items and demographic items. An alpha level of 0.05 was set to determine the level of statistical significant.

Kruskal-Wallis One-Way ANOVA. The Kruskal-Wallis one-way analysis is used to determine whether three or more nominal groups (e.g., close proximity, other proximity, none/heard of SLE, deeper educational exposure, none) are the same or different on some continuous variable of interest (e.g., scores on the LKQ or LKQ-R; Chan & Walmsley, 1997). In order to assess any differences between educational exposure and disease proximity groups across the LKQ the standard One-Way ANOVA analyses could not be completed because the data were not normally distributed; therefore, this nonparametric equivalent was utilized. The KW ranks each groups' median score on the continuous variable (LKQ scores); thus, the groups are ranked in order and it is provided in a mean rank ordering. Two very important advantages of ranking data (i.e., conducting a Kruskal-Wallis) instead of using the original data are (1) the calculations are simple and (2) few assumptions are made about the kind of distributions.

Internal Consistency. Internal consistency indicates how well the items on a measure fit together conceptually and ensures the level of consistency of answers item by item (Terwee et

al., 2007; Clark & Watson, 1995). The Kuder Richardson-20 Formula was used due to researcher agreement that it is a more appropriate statistical method to calculate dichotomous items (Wagner et al., 2005). Score values of the Kuder Richardson-20 range from 0.0 to 1.0, where a score of .70 is the low end of an acceptable score (DeVellis, 2003).

Split-Half Reliability. A second internal consistency measure was also calculated. A split-half reliability assesses the internal consistency of a test, by dividing the scale into two equal parts to test equally what is being measured (Crocker & Algina, 1986). Each half of the measure receives a Pearson r score, ranging from -1.00 to 1.00 and then each half is compared to one another. Therefore, another internal consistency score was reported: Spearman-Brown coefficient. The measurement procedure is considered to demonstrate split-half reliability if the two sets of scores are highly correlated (DeVon et al., 2007).

Item difficulty. A full range of responses is important for a novel questionnaire and those items that have limited discrepancy should be excluded. In particular, floor and ceiling effects should be examined based on item distribution (Johnson et al., 2011). The item difficulty analysis is conducted by dividing the number of individuals who responded correctly by the number of total respondents. The scores are then used to identify items that are answered correctly by more than 80% (too easy) or fewer than 20% (too difficult; Wollack, n.d; Carpenter, et al., 2009). Values are used to assess item difficulty, values range from 0.00 to 1.00 and values closer to 0.00 are considered more difficult (Sim & Rasiah, 2006). It is optimal to have a difficulty level of .75 when there are two options for a test (McCowan & McCowan, 1999). However, scores between .30 and .80 are considered acceptable.

Item discrimination. The item discrimination index is a measure of how well an item distinguishes between respondents who are knowledgeable and those who are not (Wollack, n,d).

This statistic measures the differences between the percentage of participants in the lower and upper 27% of scorers who score correctly (Sim & Rasiah, 2006). Scores range from -1.0 to 1.0 and converted into a percentage. The higher the discrimination index the better the item can determine the difference between participants who score high and those who score low on the questionnaire (Sim & Rasiah, 2006). Scores of 0.4 and higher are considered desirable items and a minimum of 0.2 has been proposed as the cutoff value below at which items should be discarded (McCowan & McCowan, 1999).

Readability. All instruments used to educate individuals should not exceed a ninth grade reading level; however, readability scores often exceed the ninth grade level (Rudd, Moeykens, & Colton, 1999). Not exceeding a ninth grade level helps to ensure that questions can be understood by a wider range of readers (Terwee et al., 2007). There are a variety of readability analyses, but there is controversy about which to use because some analyses have been found to produce different scores for the same material (Calderon, Morales, Liu, & Hays, 2006; Friedman & Hoffman-Goetz, 2006). For the current study, readability was assessed through two common measures. The Flesch-Kincaid Readability formula (FRF), which provides a grade reading level score (Kincaid, Fishburne, Rogers, & Chissom, 1975). This assesses the readability of text based on the number of syllables per word and words per sentence (Young, et al., 2002). The Flesch Reading Ease Scale (FRES) provides an age appropriate reading level. Both scores are calculated by using computer software in Microsoft Word (Coleman & Liau, 1975; Rhee, Von Feldt, Schumacher, & Merkel, 2013).

Results

Phase 1: Conducting Provider Interviews

The interviews conducted were informed by a set of items designed to represent relevant SLE knowledge domains. Three medical providers were enrolled. The interviews took 55 minutes, 38 minutes, and 1 hours and 5 minutes, respectively.

The qualitative data presented encompass the interview data gathered from the first and third sets of protocol questions (*Appendix A*). Data gathered during the second set of questions were not relevant to the creation of the questionnaire because the purpose of set two was to determine whether any SLE-specific questionnaire tools were used by the providers. They all reported that no such tool existed. Under set one, I will report on the SLE-specific content that the providers gave regarding information informed by the Common Sense Model of Illness, A) cause, B) identity, C) timeline, D) controllability, E) consequences. For the third set of interview items, I will briefly present data that the providers reiterated and added with regard to educating others.

Research Question 1. What are the common topics that providers identified as being important to be included in the Lupus Knowledge Questionnaire?

Interview Set One: Common Sense Model of Illness. Providers were asked to provide detailed topics, themes, or general facts that related to the five dimensions of the CSM. Some of the dimensions proved to be more difficult to provide facts or explicit concepts on due to the dimension not having one or a simple straight forward answer. This problem was identified throughout the interviews and it attributed to the fact that SLE is not predictable and patients experience different disease expressions (physical complications, internal organ system involvement) and severity of disease (flares; mild or severe). Nevertheless, results below

describe the range of topics that the providers give in an attempt to report clear and factual information.

Cause. The providers reported that understanding the cause of SLE requires an awareness of broad and narrow facts. Broadly speaking, providers reported that the cause of SLE is not fully understood. They reported knowing about risk factors but ultimately reported that it is difficult to identify each person's triggers or reason for the disease onset. This is why patients should be aware of the three categories of SLE cause. These include the involvement of genetics, environmental hazards, and hormones all of which are areas that the medical community has linked to SLE onset.

Beginning with genes, providers mentioned that a person has a genetic predisposition for SLE prior to the disease actually showing symptoms. For the onset to occur individuals who have the various genetic sequences and linkages for SLE must come in contact with an environmental "trigger" which then activates the mutation and the signs and symptoms begin expressing. Scientists have identified these genetic aspects of SLE. However, it is much more difficult to identify which of the environmental or hormonal triggers initiated the disease expression and there are no fail-proof ways of assessing what trigger will cause or has caused each case of SLE to activate. Nevertheless, factors that have been linked to the onset of SLE were increased exposure to sunlight, direct exposure to various hazardous chemicals, pregnancy, and increased life stress. Hereditability is important to understand because it can allow for someone to be aware that they have or may have the genetic predisposition for SLE.

Identity/Symptoms. The providers' discussions regarding symptoms unanimously supported the notion that patients need to know that the general severity of symptoms vary. Just as the specific triggers are hard to identify for each individual patient, each person's experience

with symptom expression and severity are often unique to him or her. It was reiterated that being aware that the intensity of symptom expression can help patients learn to manage their disease better. Although severity may vary, many symptoms are quite similar. The providers included both visible and invisible symptoms, but highlighted the increased number of invisible symptoms that patients experience.

The providers mentioned the chronic symptoms of SLE and how more flares occur but many internal symptoms can only be identified by test results. The providers emphasized the extreme fatigue and chronic stiffness and joint pain that occurs. These symptoms were discussed as the first indicators of rheumatologic conditions but the symptoms are often disregard by patients and providers. Patients tend to wait to seek answers because they attribute their tiredness and soreness to other stressors, concerns, or conditions. One provider mentioned that he tends to see patients once the accumulation of symptoms already occurs. These include weight gain or loss, hair loss, loss of circulation in the hands (causes the hands to take on a blue tint), facial skin rashes, digestive system issues, and increased feelings of depression. These symptoms are also often missed by medical providers because they can be common in other conditions.

The final set of symptoms that the providers discussed were the medical tests used to confirm an SLE diagnosis. They named some commonly used diagnosis tests, which included the antinuclear antibodies (ANA), platelet count, antibodies to double-strand DNA (anti-dna), and antibodies to phospholipids (aPLs). These tests are not often run until a multitude of other conditions have been ruled out. For instance, the ANA is the most commonly used diagnostic test. However, its scores can become elevated for other reasons, thus, a high rate of false positives and false negatives occur for patients. Therefore, a combination of these various antibody tests and blood draws need to be run to gather enough data to confirm a diagnosis.

In order to have a diagnosis of SLE, a patient must have a combination of the physical symptoms and medical test results. The providers highlighted how important it is that patients tell their doctor when they experience any physical symptoms. One provider mentioned that he hopes patients always hold their own feelings in high regard and express to their providers when they feel "off" because patients are the best reporters of their own experiences. He believed that patients are ignored by their physicians too often. Therefore, in order to identify symptoms early and begin treatment patients must be an active reporter of their experiences.

Course/Timeline. It is important for patients to understand that this is a chronic disease and they will have it forever, but their life does not end when they receive a diagnosis. The providers reiterated that patients need to understand that the diagnostic process is lengthy and the timeline to receive a diagnosis varies greatly. However, two of the providers reported that they are much more familiar with various SLE signs and symptoms than other medical professionals; therefore, they are able to diagnose the patient earlier. They reported that many other providers not familiar with SLE do not pay much enough attention to the accumulation of symptoms and end up writing their patients off. All three reported this as a common concern and reason for why the process of receiving the diagnosis is so lengthy.

As a rheumatologist, one provider receives referrals for recently diagnosed patients. He reported having different objectives when it comes to considering an SLE timeline. His concerns involve understanding how long the disease had been present prior to the official diagnosis because that timeline is critical for understanding the amount of damage that has occurred. Knowing those details informs him about what the appropriate medication regimen involves. The earlier the treatments can begin the less damage occurs in the body. There is no "one rule fits all" when it comes to diagnosing and treating.

Controllability/Curability. The providers unanimously agreed that patients need to understand that SLE is not a death sentence. The providers reported optimism in current treatments and highlighted how the disease can be managed with treatments. In order to control SLE, patients must know their body and how their day-to-day activities influence how they experience their SLE. For instance, paying attention to symptoms is critical for helping control the ebbs and flows of symptom severity. One day a patient may feel very healthy while the next they may feel extremely sick. In order to better control their SLE patients must alter their lifestyle to ensure they do not exert themselves too much.

Medications have been adapted over the last 20 years and the providers reported that they have positive effects when taken correctly and consistently. Patients must understand how important it is to know their medications and understand that some medications (e.g., steroids) have quite harmful long term effects while other medications (e.g., anti-inflammatories) are taken daily to ease aches and pains. Ensuring accurate adherence will help minimize severe flares. SLE can be managed by medications but receiving the appropriate dosage is a process that requires patient-provider collaboration and teamwork. Additionally, it is important that patients understand that SLE is not contagious. The fear of giving it to another person is a common misconception.

Consequences. The providers were asked to discuss how an SLE diagnosis influences a patient's life: socially, physically, and mentally. The providers elaborated that the majority of their previous and current patients express a concern about the ability to "maintain their previous life." Patients do not want to feel limited by their diagnosis and so learning how to manage their disease is beneficial and helps patients become more optimistic. Increasing social support helps increase optimism, as does learning to monitor one's physical and mental experiences. Co-

morbid diagnoses of depression and/or anxiety after receiving an SLE diagnosis are common and contribute to the shift in patient's lives.

The providers mentioned how patients are often scared and confused by their diagnosis and tend to believe that they cannot maintain their physical lifestyle. The providers agreed that when a patient manages their SLE and participates in their treatments their life does not need to change dramatically. However, they do warn that because of the variability of symptom severity neither they nor a patient can be sure what each day will look like. Therefore, caution must be taken. Even more, many patients with SLE often end up being unable to work.

To ensure that a patient's SLE is managed, he or she must monitor their lifestyle. Common topics related to lifestyle management included maintaining a moderately active lifestyle (e.g., nonaerobic), incorporating healthy diet (e.g., minimize meat and gluten), minimize prolonged sun exposure, no smoking, and correct medication management. Looking towards one's future and being aware of his or her increased risk of comorbid diagnoses is an additional reason that proper lifestyle management needs to occur. Prolonged SLE consequences are quite severe and include neurological concerns (e.g., memory), digestion issues, cardiovascular health, and circulatory function.

Interview Set Three: Additional Information for Others. During set three, providers were asked to report on what information related to SLE was important for other people (e.g., family, friends, social supports, general public) to know. The goal was not only to gain information about SLE facts relevant for patients but also to know if additional aspects of SLE knowledge were important for others to know about SLE. The emphasis in this section was to encourage the providers to give any reiteration of themes already mentioned and to allow for further elaboration.

General Information for Others. Overall, the providers reiterated many similar themes that they had mentioned during set one. The providers discussed that a portion of distress patients experience occurs because of others being misinformed and uneducated about SLE. Therefore, it is important to help educate family and supporters about SLE. Providers discussed noticing that those who interact with patients are just as scared and confused as patients are of the complexities of SLE. Increasing awareness of SLE and how it is experienced might be the first step in helping create an educated support network for patients.

Specific for Family. When it comes to educating the family members, it is more important to understand who the patient wants involved in their care rather than presuming who is important to inform. This is because support is not unidimensional and patients may bring their spouse, child, parent, or friend with to a doctor's appointment. Thus, increasing the awareness and knowledge that those individuals have of SLE should take priority. This is important to understand because these support individuals are in the appointment with patients when the doctor explains any concerns or results. That supporter should be able to remain active and involved in the appointment alongside the patient. This means having a thorough understanding of SLE. This is an additional way to encourage better collaborative communication between all parties. One provider said that he believes patients have so much on their mind that having an informed supporter with them is essential.

Two phrases that the providers mentioned as being unwarranted misconceptions about SLE were "it's all in their head" and "…but you look fine." These two phrases relate to the invisibility of SLE and therefore other people are unable to see the effects of SLE. SLE is a disease and it is not "in their head." If SLE manifested on the outward appearance people might begin to understand how detrimental it is on the person. However, because people cannot see the

internal deterioration of SLE they use this phrase. Phrases such as these belittle and minimize the realities of SLE. Patients need to know that these phrases are false and it is equally important that family and the public understand that although symptoms are not seen, they are felt. Providers reiterated how often family and friends of SLE patients believe that the patient is crying wolf or exaggerating to receive pity. This misconception about invisible illness is a major downfall in creating a supportive environment for patients. Therefore, increasing others' awareness that even though the patient may look okay on the outside their internal body is not okay.

Specific for General Public. The providers were aware that this measure would be used to assess two general public samples' knowledge of SLE and thus they were asked if they had different considerations about how to increase community knowledge. They all agreed that this goal is ambitious and hopefully one day we can say that the public is aware and knowledgeable but that is far in the future. One provider mentioned that the best hope we have for informing the public is to educate the public about invisible diseases overall, not just SLE. The general comment regarding educating the public is to understand that this illness is not a death sentence and that it is not contagious, which are two common misconceptions that increase the stigma surrounding SLE.

Phase 2: Reviewing Patient Education and Interview Data

Creating the LKQ Items. For the draft version of the LKQ, the items' content had been chosen if such content had been brought up during the interviews with the medical providers and/or if the SLE facts were in the LFA's packets (DeVon, et al., 2007). There is a wide range of important SLE facts that were identified by the providers. Therefore, to ensure that the LKQ could be used as a general knowledge tool and not contain highly specific and jargon information the content was chosen selectively. For example, the providers discussed various details

regarding medication regimens that would be important for patients to know, but not necessary for the community to know.

Conducting Directed Content Analysis. The Common Sense Model of Illness (CSM) was used to guide the theoretical foundation of the present study. In order to inform the LKQ, the dimensions of the CSM (identity, cause, timeline, controllability/curability, consequence) were used to generate items. For example, the draft version of the LKQ contained 38 items and of those items, 13 were coded as *cause.* Nine items were coded into the *consequence* dimension; eight items were coded as *curability/controllabilit*y, seven items were coded for *identity*, and three items were in the *timeline* dimension. (See *Appendix E for LKQ and CSM.*)

Phase 3: Verifying and Revising LKQ Draft.

The draft version of the LKQ was created, verified by providers and tested for various item analyses (e.g., readability and item difficulty). Those results are described below. Edits from such revisions were applied to the revised version of the LKQ, which was administered to the second community sample.

Readability. For the draft version of the LKQ, the Flesch-Kincaid grade level or FRES score was 8.9, which indicated a ninth grade reading level. The overall scale was grade appropriate (Rudd, Moeykens, & Colton, 1999; Terwee et al., 2007). However, one item maxed out at 16.5 (lupus increases an individual's risk of premature cardiovascular disease (heart disease)), but others were as low as a second grade reading level (Hair loss in a symptom of lupus, 2.3). For the Flesch-Kincaid readability formula (FRF) the score was 49.0 which is considered "very difficult" (Friedman & Hoffman-Goetz, 2006). The scores ranged from 10.5 (bipolar disorder is the most common co-occurring mental health diagnosis) to 95.9 (lupus is caused by the same virus that is linked to HIV); see Table 6 for full item difficulty scores.

Overall, the grade level score of the draft version satisfied the recommended grade level readability.

Content Verification. After the survey was drafted, the three medical providers were asked to verify the content of the draft version and provide feedback regarding item accuracy and clarity. For the draft version of the LKQ, items were created based on the content analysis from phase two. All of the results follow; to see which items were retained or excluded based off various analysis methods refer to Appendix D.

Content Validity Index. The providers were asked to provide relevance ratings on the Content Validity Index (CVI) for each item of the LKQ-draft (1= *not relevant*, 4= *highly relevant*) and provide any additional feedback. A rating of three or four indicated the content was perceived as valid and consistent with the conceptual framework of general SLE knowledge, whereas, items rated one or two were considered irrelevant and unnecessary, unless, the providers gave accuracy feedback (Lynn, 1996). Items that were deemed irrelevant (CVI score of 1 or 2) were deleted unless a provider gave written feedback, the feedback was intended to create a relevant item. The items with feedback were edited and retained for the revised version. The items that were deemed relevant (CVI score of 3 or 4) were retained. An item score of .80 (4/5 providers) has been cited for being on the low end of acceptability for item retention (Lynn, 1986); however, researchers have indicated that a score of .67 (2/3 providers) is acceptable (Polit, Beck, & Owen, 2007). Therefore, if at least two of the providers gave a score of 3 or 4, that item was retained. There were two expectations. Items number 6 and 21 on the draft version were excluded from the revised version due to my subjective opinion of making cuts to the length of the questionnaire and because both are relative for the patient and potentially tap into perceptions of SLE rather than strict knowledge.

All three providers agreed that two of the items were not relevant (score of 1 or 2). Eleven items were unanimously agreed upon as is as being relevant (score of 3 or 4). Provider 1 provided additional comments for 13 of the 38 items, provider 2 provided comments for 9 of the 38 items, and provider 3 opted to give no written feedback. Of the 38 items that were included on draft LKQ, 28 items were edited for clarity or accuracy (See Appendix D: Verification Feedback from Providers). At the end of the verification process, the l I-CVI scores ranged from 1.00 (3/3 agreement) to 0.00 (0/3 agreement).

Regression Analysis. A regression analysis was used to test which of the 38 items of the LKQ accounted for the most predictive value for LKQ scores. The 38 items were analyzed within a forward regression analysis and the analysis indicated that thirteen items explained 92% of the variance (R^2=.920, F (1,322) = 5.270, p = .022) of the knowledge scores. Those thirteen items significantly predicted the overall score on the LKQ. These data contributed to the decision to keep various items because the items' associations with predicting participants who scored better on the LKQ. Additionally, the data from the regression analysis further supported the results from the CVI. The regression analysis results can be found in Table 5.

Item Difficulty. In addition to the items retained based on the CVI and regression analysis data, three more items were retained from the draft version to the revised version because of my subjective reasoning and the exploratory item difficulty scores they received. Item number 36 (bipolar), 38 (Caucasian more than others), and 17 (jaundice) were kept because during the exploratory item analysis (discussed below) these three items results in more appropriate difficulty scores due to better distributions of true and false responses. Therefore, these items were considered key items that were not too easy, but also not too difficult. Additionally, all three of these items incorporate concepts that were directly related to what the

providers discussed and information mentioned in the pamphlets. Together, these two reasons warranted enough support to add them to the revised version to further assess their value as LKQ items. To see each item's difficulty score, see Table 6.

Phase 4: Testing the LKQ and LKQ-R

Community Sample 1. The LKQ was administered to the first community sample. The results of the first administration of the LKQ are presented below.

Demographic. There were a total of 345 young adults screened from a community sample to be included in the first administration of the LKQ. However, seven participants' data were excluded because they omitted all 38 items on the LKQ. The final sample size included a total of 336 participants. The assumption of normality was assessed using the recommended Shapiro-Wilk test to determine if the LKQ scores were normally distributed (Ghasemi & Zahediasl, 2012). The first sample was reviewed based on the Shapiro-Wilk (SW=.743, df=336, $p > .001$), skewness (1.301), and kurtosis (.562) and the findings suggested that the normality assumption was not met. Therefore, nonparametric analyses were used.

Research Question 2. How do participants in a community sample (the young adult) score on the LKQ?

Lupus Knowledge Questionnaire. The draft version of the LKQ contained 38 items that assessed general SLE knowledge. Data from the 336 participants were examined to determine the level of knowledge the participants had of SLE. Overall, 160 participants (47.6%) scored a zero on the LKQ. The average score on the LKQ was 16.34% (SD= 23.07%) and scores ranged from 0% to 92% (Figure 1: LKQ-draft Scores)**.** No participant answered all 38-items correctly. Two participants scored the highest with a 92% or 35/38 items answered correctly. Only 45 participants scored a 50% or higher on the LKQ (13.4%) and 155 (46.1%) participants indicated

having no knowledge of SLE by choosing "don't know" for all 38 items. The majority of the participants reported, "don't know" for all items (*Table 7: response rates for each draft item*).

The first sample administration of the LKQ exhibited good internal consistency (Kuder Richardson-20 = .960). Items were coded as 0 and 1's, in that correctly answered items incurred a coding of 1, while both incorrectly answered and "don't know" responses were coded as 0. Split-half reliability was also conducted and exhibited an excellent reliability score (Spearman-Brown =.931)

Item Difficulty. Item difficulty analyses were calculated for each item. Each score is represented by a value, ranging from 0 to 1.00. The closer an item's score is to 1.00 indicates that more participants answered the item correctly while scores closer to 0.00 were answered correctly by fewer participants. Item difficulty scores varied for each item based on the number of responses accounted for. For the 38 items, item difficulty scores ranged from 0.027 to 0.298. As referenced previously, scores ranging between .3 and .8 are ideal (McCowan & McCowan, 1999). Therefore, scores were unanimously indicative of a very difficult questionnaire. However, due to the high degree of "don't know" responses the low scores were expected. The item difficulty scores for each item are presented in Table 6.

An exploratory item difficulty analysis was also conducted to gain perspective of the items without the high rate of "don't knows." Scores were calculated by accounting for participants who responded with either true or false (i.e. those who felt confident in their knowledge and attempted the answer the item) without accounting for the "don't know" responses. For the 38 items, the exploratory item difficulty scores ranged from 0.283 to 0.971. The purpose of exploring these scores was to assess the hypothesized item difficulty scores that may have been more appropriate with a sample that would have been more knowledgeable.

Item Discrimination. Due to the skewed scores of the entire sample (almost half of the participants received a score of zero), item discrimination could not be calculated. The item discrimination scores would traditionally be calculated when wanting to identify which items can discriminate between overall scores of respondents who did well and those who did not. For example, to assess each item's discrimination value, the percent score of the item that was attained by the top 27% would be subtracted from the percent score of the percent score attained by the lower 27% of the participants who answered that item. Therefore, the equation would look similar to this, *16% - 0% = 16%*. This sort of discrimination score indicates that the item is unacceptable (Sim & Rasiah, 2006).

Educational Exposure to SLE. Participants were asked to report their current level of educational exposure to SLE. When asked whether the participants had heard of SLE, the large majority reported yes (N=245, 72.49%). However, when asked about their further exposure to the disease, affirmative responses diminished greatly. When participants were asked had they read about SLE, learned about SLE in a class, or attended a lecture on SLE the large majority reported no for all three, respectively (N=272, 80.47%; N=293, 86.43%; N=331, 97.93%).

Disease Proximity to SLE. Participants were asked to report any disease proximity to SLE by indicating if they had a personal diagnosis, a family member (immediate or extended) diagnosed and/or if they knew any other person living with SLE. If they reported "yes" they were asked to identify the relationship of that individual (e.g., friend, neighbor, mother-in-law). Participants were given the option to not respond to these items without repercussions. Of the 328 who replied when asked about a personal diagnosis, only three participants reported personally having a diagnosis of SLE (0.09%) and twenty-two reported knowing a family member (immediate=8; 2.4%, extended=14; 4.6%) who has a diagnosis. An additional 34

participants reported knowing some other person with an SLE diagnosis (10.4%; Table 2: Disease Proximity Frequency).

Perceptions of Knowledge. Participants were asked to report on how confident they were of their current accuracy of SLE knowledge prior to taking the LKQ. Only seven participants reported feeling "*confident*" in their knowledge and an additional five felt "*extremely confident,*" totaling only 3.6% of the sample. The remaining 323 participants reported either no confidence, some confidence or that they were unsure (N=238, 70.8%; N=49, 14.6%; N=36, 10.7%, respectively).

Participants were also asked to report how they perceived their own knowledge of SLE compared to the average person. Only a total of 8% of the sample believed they had more knowledge of SLE than the average person (*Much More Knowledge* = 5; *More Knowledge*= 22). Ninety-one participants reported having *less knowledge* than the average person (27.1%). The highest group reported that they had *much less knowledge* about SLE than the average person (N=114, 33.9%). The rest reported believing they had the *same level of knowledge* as the average person (N=101, 30.1%). Overall, people believed they had less knowledge of SLE than the average person.

Hypothesis 1. Individuals with educational exposure to SLE will have higher scores on the LKQ than those who have no exposure to SLE.

A Kruskal-Wallis one-way ANOVA was conducted to assess rank differences between the educational exposure groups. Group 1 consisted of participants who had heard of SLE (N=160), group 2 consisted of those who had endorsed at least one of the other exposure items (read about SLE, attended lecture, and/or read about it; N=86), and group 3 consisted of those who had reported having none of the above educational exposures (N = 89). Results indicated

that there was a statistically significant difference in LKQ scores earned by those with different educational exposure, $\chi^2(2) = 96.12$, $p < .001$, with a mean rank of 169.85 for group 1, 235.25 for group 2, and 99.69 for group 3.

A post hoc sums test indicated that participants who reported having heard of SLE (group 1; 105.45) scored significantly lower on the LKQ than those who had had a deeper educational experience (group 2; 157.16), $\chi^2(1) = 30.83$, $p < .001$. Secondly, participants who reported having learned about it in a deeper educational experience (group 2; 122.51) scored significantly higher on the LKQ than those who reported no educational exposure (group 3; 56.01), $\chi^2(1) = 30.83$, $p < .001$. Similarly, individuals who had heard of SLE (group 1; 145.73) scored significantly higher on the LKQ than those who reported no educational exposure (group 3; 89.54), $\chi^2(1) = 43.22$, $p < .001$.

Hypothesis 2. Individuals who have closer proximity to SLE will have higher scores on the LKQ than those who indicate having no proximity to SLE.

A Kruskal-Wallis one-way ANOVA analysis was conducted to assess rank differences between the disease proximity groups. Group 1 consisted of those who self-identified as having SLE and/or indicated an immediate or extended family member had SLE (N=22). Group 2 consisted of those who indicated that they knew someone else with SLE (N=29). Group 3 consisted of people who reported that they knew no one with SLE (N=276). Results indicated that there was a statistically significant difference in LKQ scores earned by those with different disease proximity, $\chi^2(2) = 36.23$, $p < .000$, with a mean rank of 245.84 for group 1, 222.40 for group 2, and 151.34 for group 3.

A post hoc rank sums test indicated that participants who reported having close proximity (group 1; 27.84) did not statistically differ from those who reported knowing someone else with

SLE (group 2; 24.60), χ^2 (1) = 0.60, p = .440. However, those with close proximity to SLE (group 1; 229.50) compared to those with no proximity (group 3; 143.12) scored significantly higher on the LKQ, χ^2 (1) = 23.28, p < .001. Similarly, those with other proximity (group 2; 212.79) compared to those with no proximity (group 3; 146.72) also scored significantly better on the LKQ, χ^2 (1) = 16.78, p < .001.

Community Sample 2:

Demographic. The final sample size for the administration of the LKQ-R was 188 participants because those participants correctly answered the validity item. The assumption of normality was assessed using the recommended Shapiro-Wilk test (Ghasemi & Zahediasl, 2012). The second sample was reviewed based on the Shapiro-Wilk (SW=.743, df=336, p > .001), skewness (1.301), and kurtosis (.562) the findings suggested that the assumption of normality was not met. Therefore, nonparametric analyses were used.

Research Question 2. How do participants in a second adult community sample score on the LKQ-R*?*

Lupus Knowledge Questionnaire-Revised. The revised version of the LKQ used in the second sample contained 34 items. Of the 188 participants, no one received a score of zero. Seventeen participants received a score of 3% by getting 1/34 items correctly (9.0%). The average score on the revised version was 41.16% (SD= 22.80%) and scores ranged from 3% to 94%**.** Overall, no participant answered all 34 items correctly. Only one participant scored the highest with a 94% or 32/34 items answered correctly. Seventy-five participants scored a 50% or higher on the LKQ-R (39.89%). Figure 2 provides a pie chart of the LKQ average range scores for the second sample (see Table 13: LKQ-R Response Rates). For the revised version of the

LKQ, items were retained based on CVI scores, a regression analysis, and information gathered through the item difficulty analysis.

The LKQ-R exhibited good internal consistency (Kuder Richardson-20 = .940). Items were coded as 0 and 1's, in that correctly answered items incurred a coding of 1, while both incorrectly answered and "don't know" responses were coded as zero. Split-half reliability was also run and exhibited good reliability (Spearman-Brown Coefficient= .889).

Participants were asked whether they had educational exposure and disease proximity. Therefore, in order to assess if those who reported educational exposure also more commonly reported disease proximity a chi-square analysis was conducted. The analysis indicated that there was a statistically significant association between those who identified as having proximity to SLE and those who identified having educational exposure to SLE, $X(6)=14.988$, $p =.0.020$. The Phi value (.284, p=0.020) indicates a medium strength association.

Readability. For the final version, the overall Flesch-Kincaid grade level or FRES score was 8.7, indicating a near ninth grade reading level, which is appropriate (Rudd, Moeykens, & Colton, 1999; Terwee et al., 2007). The score range for individual items decreased after edits occurred for the revised version to be between a score of 3.6 (treatment can cure lupus) 13.9 (bipolar disorder is the most common co-occurring mental health diagnosis for lupus patients). For the Flesch-Kincaid readability formula (FRF), scores range from 0 (*very difficul*t) to 100 (*very easy*). The score scale's score was 49.6, which is considered difficult (Friedman & Hoffman-Goetz, 2006). The scores ranged from 17.9 (bipolar disorder is the most common co-occurring mental health diagnosis for lupus patients) to 82.3 (hair loss/thinning is a symptom of lupus); see Table 12 for item's score. Overall, changes on the FRES and FRF slightly improved.

Certain items that contained more jargon language (e.g., cardiovascular disease, bipolar, co-occurring) incurred higher ratings of difficulty, which increased the score. Items were not deleted based on their FRES or FRF score because some items were in the appropriate range for one or the other score (e.g. either reading ease or grade level). Additionally, previous researchers have had items that exceed the aimed score, but because their overall score remained appropriate the items were retained but incorporated further explanations (e.g., heart disease and explaining genetic predisposition; Rhee et al., 2013).

Item Difficulty. Item difficulty was calculated for each item. Each score is represented by a value ranging from 0 to 1.00. The closer the score was to 1.00 the more participants answered the item correctly and items with a score closer to 0.00 were answered correctly by fewer participants. Item difficulty scores ranged from 0.048 (item 23, immune count test) to 0.711 (item 25, immune system weakened). Even though item 20 revised a score of 1.00, it was not included in the difficulty range, because this item was used as the validity item and everyone included answered that item correctly. The item difficulty scores for each item of the revised version are presented in Table 12.

Item Discrimination. For the second sample, scores were more variable without the influx of don't knows and zeros and therefore, item discrimination was calculated. The higher the discrimination index the better the item can determine the difference between participants who score high and those who score low on the questionnaire (Sim & Rasiah, 2006). Scores of .40 and higher are considered desirable (McCowan & McCowan, 1999). Items on the revised version were calculated for item discrimination by computing the differences between the top 51 participants and the bottom scoring 51 participants (top and bottom 27%). Discrimination scores ranged from 11.7% to 85.1%. Only three of the 34 items received an "unacceptable" score (item

23,30,32); however, these items provided insight for what presumptions are believed by many community members. For this reason, they should be retained for further examinations of the efficacy of the LKQ-R (see Table 12).

Educational Exposure to SLE. Participants were asked to report their current level of educational exposure to SLE. When asked whether participants had heard of SLE, the large majority reported yes (N=179, 95.2%). Almost half the sample reported having read about SLE (N=84, 44.7%). However, only six participants reported having attended a lecture on SLE (3.2%). Finally, 24 participants reported having learned about SLE in a class (12.8%; see Table 11: Educational Exposure Frequency).

Proximity to SLE. Participants were asked to report on their proximity to SLE. The participants were asked to report on a personal diagnosis, a family member diagnosis and/or any other person they know diagnosed with SLE. If they identified a person, they were asked to describe the relationship of the individual. Participants were given the option to not respond to the following items without being penalized. Of the 188 participants who were included in the final analyses, 186 participants opted to reply to the disease proximity items. When asked about a personal diagnosis, three participants reported having a diagnosis of SLE (1.6%) and twenty-two reported having a family member (immediate= 4, 2.1%, extended=18, 9.6%) diagnosed. An additional 48 participants reported knowing some other person with SLE (25.5%; see Table 9: Disease Proximity Frequency).

Perception of Knowledge. Prior to taking the LKQ-R, participants were asked how confident they were of their SLE knowledge. Only ten participants (5.3%) reported feeling *confident* in their knowledge and just one participant reported feeling *extremely confident*, together accounting for 5.8% of the sample. Half of the sample reported having no confidence in

their knowledge (N=94, 50.0%). While another 25% of the sample reported having some confidence (N=47). The remaining participants reported being unsure about their knowledge of SLE (N=36, 19.1%).

Following the LKQ-R, participants were asked to report on how they believe their level of knowledge compared to the average person. Almost half of the sample reported having the *same knowledge* that the average person has (N=92, 48.9%). A total of 59 participants reported having *less knowledge* (N=33, 17.6%) or *much less knowledge* (N=26, 13.8%) than the average person. However, 37 participants reported feeling as though they had *more knowledge* (N=31, 16.5%) or *much more knowledge* (N=6, 3.2%) than the average person.

Hypothesis 1. Individuals with educational exposure to SLE will have higher scores on the LKQ than those who have no exposure to SLE.

A Kruskal-Wallis one-way ANOVA was conducted to assess the relationship between LKQ-R scores and participants' educational exposure. Group one consisted of those who had heard of SLE (N=93), group 2 consisted of those who had endorsed at least one of the other exposure items (read about SLE, attended lecture, and/or read about it; N=85), and group 3 consisted of those who had reported having none of the above educational exposures (N = 9). Results indicated that there was a statistically significant difference in LKQ scores earned by those with different educational exposures $\chi^2(2) = 47.09$, $p < .001$, with a mean rank of 68.51 for group 1, 123.66 for group 2, and 77.33 for group 3.

A post hoc sums test indicated that participants who reported having a deeper educational experience with SLE (group 2; 116.75) scored significantly higher on the LKQ than those who had only heard of SLE (group 1; 64.59), $\chi^2(1) = 45.59$, $p < .001$. Additionally, participants who reported having learned about SLE in a deeper educational experience (group 2; 49.91) scored

significantly higher on the LKQ than those who reported no educational exposure (group 3; 24.78), χ^2 (1) = 6.92, p =.009. However, the LKQ scores for individuals who had heard of SLE (group 1; 50.91) did not differ significantly compared to those who reported no educational exposure (group 3; 57.56), χ^2 (1) = 0.42, p =.519.

Hypothesis 2. Individuals who have closer proximity to SLE will score higher on the LKQ than those who indicate having no proximity to SLE.

A Kruskal-Wallis one-way ANOVA was completed to assess the relationship between LKQ-R scores and disease proximity. Group 1 consisted of those who endorsed having a personal SLE diagnosis and/or those who indicated having a family member (immediate or extended) with SLE (N=21). Group 2 consisted of those who indicated that they knew someone else with SLE (N=43). Group 3 consisted of people who reported that they knew no one with SLE (N=122). Results indicated that there was a statistically significant difference in LKQ scores earned by those in different disease proximity groups, χ^2 (2) = 16.044, p < .001, with a mean rank of 124.40 for group 1, 109.80 for group 2, and 82.43 for group 3.

A post hoc rank sums test indicated that participants who reported having a close proximity (group 1; 36.31) did not statistically differ between those who reported knowing someone else with SLE (group 2; 30.64), χ^2 (1) = 1.312, p = .252. However, both group 1 and group 2 scored significantly higher on the LKQ than those who indicated knowing no one with SLE. Those in the close proximity group (group 1; 99.10) compared to those who reported no proximity to SLE (group 3; 67.34) scored significantly higher on the LKQ, χ^2 (1) = 10.55, p = 001. Similarly, those who reported knowing someone else with SLE (group 2; 101.16) compared to participants who reported knowing no one with SLE (group 3; 76.60) scored significantly higher on the LKQ, χ^2 (1) = 8.421, p =.004.

Discussion

The purpose of this study was to 1) create a novel SLE disease-specific knowledge questionnaire and 2) assess the knowledge of community members using the LKQ. The specific hypotheses were created to assess whether having learned about SLE in an educational setting (i.e., educational exposure) as well as the effects of knowing about SLE on a more personal level (i.e., disease proximity) were related to scores on the knowledge questionnaire. A four-phase design was used to execute the study; the initial three phases involved the foundational work of creating the SLE knowledge questionnaire and the final phase consisted of administering the LKQ to two unique samples. Hypothesis one was supported: those with deeper educational exposure to SLE earned a higher score on the LKQ than those with no exposure. Hypothesis two was also supported: those with closer disease proximity to SLE earned a higher score on the LKQ than those with no proximity. Further findings also emerged and are reviewed below.

Results of Research Question 1

In order to create a medically accurate knowledge questionnaire interviews with medical provider were used. The interviews were the foundation of research question 1, which was to determine what topics related to SLE medical providers believed were important to be included in the novel Lupus Knowledge Questionnaire.

Understanding the experience of a chronic illness involves understanding that illness is a complex process where disease-specific information is constantly being added, subtracted and adapted throughout the life (Hale, Treharne, & Kitas, 2007). Just as the providers reflected, understanding the experience of SLE is not unidimensional. Thus, the Common Sense Model of Illness was chosen as the theoretical framework to support the interviews because of its supported of the comprehensive evaluation of the dimensions of life with a chronic illness

(Cause, Identity, Timeline, Controllability/Curability, Consequence; Diefenbach & Leventhal, 1996; Hagger & Orbell, 2003).

Responses related to the *cause* of SLE involved mention of the involvement of genetics, environmental hazards, and hormones all of which have been linked to the onset of SLE (Sestak et al., 2007; Marengo et al., 2012; Crampton, Morawski, & Bolland, 2014). Although not all trigger factors have been identified, many known risk factors include exposure to sunlight, direct exposure to various hazardous chemicals, pregnancy, and increased life stress.

Discussions of the *identity* (i.e., symptoms) of SLE involved mention that each case looks differently, so although many symptoms are common the variability of experience between each SLE case varies between mild and severe, which has been substantiated in previous work assessing SLE (Sutanto et al., 2013) A number of symptoms linked to SLE that the providers mentioned, including invisible and visible. The course or *timeline* of SLE resulted in some variability in answers from the providers because the disease can be difficult to identify and diagnose. The repercussions of the lengthy diagnostic process and how important it is that treatments are started early is important for having a more controlled disease (Giffords, 2003).

Understanding SLE involves recognizing that the disease is *controllable*, but not *curable*. SLE is a chronic condition; however, due to medical advances, it is much more manageable. Two common misconceptions that the providers discussed were that SLE is a death sentence and that it can be caught (e.g., sexually or through saliva). Previous research has indicated that some reasons that patients do not adhere are because they have a decreased perception of the necessity of medication use, belief that other non-medical treatments are better, and do not have a clear understanding of the importance of the medication for SLE treatment (Carder, Vuckovic, &

Green, 2003; Chambers et al., 2009; Harrold & Andrade, 2009; Williams, Manias, & Walker, 2008). Understanding how SLE occurs is again important for understanding how to control it.

The *consequence* informed the understanding of how patients work to understand and adapt their life to understand how to now live with their disease. SLE has the potential to influence physical well-being as well as social and mental well-being (Kool et al., 2010; Kool & Geenen, 2012). Patients also are at increased risk of comorbid diagnoses, both mental (e.g., depression, anxiety; Nery et al.,2008; Bachen et al.,2009) and physical (e.g. fibromyalgia; Lam & Petri, 2005). Therefore, patients must involve a high level of symptoms monitoring, which becomes one of the main objectives after a diagnosis is received (Lam & Petri, 2005). Management of daily activities and specific health behaviors were mentioned by the providers as being important. These behaviors included maintaining a moderately active lifestyle (e.g., nonaerobic), incorporating a healthy diet, avoiding prolonged sun exposure, quitting smoking, and practicing correct medication management. Practicing these modifications minimize the severity of SLE symptoms as well as minimize the likelihood of further disease consequences (e.g., neurological concerns, heart disease (Parrondo, 2011; Lam & Petri, 2005).

The majority of the interview time was spent discussing topics related to the needs of patients; a portion of time was spent discussing what family, friends, social supporters, and the general public should know about SLE. Many of the topics mentioned previously were reiterated as being important for these other individuals. Especially supporters, people who interact with patients daily or who accompany patients to office visits should be knowledgeable of SLE. The knowledgeable support of a family member or spouse has been found to ease the worries that patients have when visiting doctors (Karlson et al., 2004). Just as there were two common misconceptions mentioned that newly diagnosed patients often report, two misconceptions that

need to be eliminated for supporters and the public's repertoire are: "it's all in your head" and "…but you look fine." These misconceptions diminish the experience of SLE for the patient's daily life and perpetuate the negative stigma that is associated with invisible illness.

Results of Research Question 2

Phase 4 consisted of determining how participants scored on the LKQ, which provided initial psychometric data for the LKQ. Two samples worth of data were collected, with one sample being administered the draft version of the LKQ and the second sample was administered a revised version.

The results gathered from sample one became influential learning steps that informed the creation of the revised version used in sample two. The information learned through the item analyses indicated that the scale had good reliability, which is essential for laying the foundation for a new measure to be trusted. However, item difficulty scores were low and indicative of extremely difficult items. Even more, item discrimination was not conducted because of the inappropriate representation of knowledge from the sample. Item analyses, although resulted with values the trustworthiness of the values is called into question. Overall, the findings from sample one's examination of the LKQ and the results of the content validity index feedback, the regression analysis, and the item analyses informed the revised version.

Participants in sample one scored quite poorly on the LKQ with only averaging about a 16%, largely contributable to the 46% of participants who choose all "don't knows." The large number of participants who scored zero skewed the overall samples interpretation values. Therefore, after recognizing this influx in don't know response a validity item was used in sample two. Overall, sample one's scores were likely influenced by three concerns; 1) the sample consisted of young adults which often times results in lack of attention to the questionnaire; 2)

the large majority of don't know responses skewed the overall scores; 3) there was no validity item in sample one. Therefore, the results gathered in sample one are not as reliable as sample two's results. Although the results of sample one were not as trustworthy, the findings were informative of how to make improvements for sample two.

Identifying the challenges and results from sample one helped inform revisions that improved the LKQ-R. A weakness in the design from sample one was that there was no way to exclude for participants who did not provide full effort in responding to the knowledge questionnaire. Therefore, the addition of the validity item improved the trustworthiness of the data from the second sample. This can be evident because the item difficulty scores were almost all exclusively in the appropriate range as were the item discrimination scores. The improvements to the LKQ-R resulted in more appropriate analyses. Together, these findings suggest that the revisions made to the LKQ to create the LKQ-R improved the overall clarity of the results. An alternative explanation is that the participants had increased familiarly with SLE and were able to exhibit a better range of knowledge. Further assessment of the questionnaire should continue.

Overall, the inclusion of a validity item on the LKQ-R was likely the most influential edit that occurred. One criticism of having a True, False, and Don't Know response format is that participants can receive an "out" by choosing all don't know and thus, they choose only don't knows (Beatty & Herrmann, 1995). The validity item allowed for me to be able to identify those individuals who did not provide their full attention to the questionnaire and used the don't know option as an "out." The scores on the revised LKQ increased, with an average score of about 41%. The results indicated that a positive shift towards better scores occurred over the two studies.

To supplement the focus of the current study and explore participants' performance on the LKQ and LKQ-R they were asked to rate their pre- and post- test perceptions of their SLE knowledge. The majority of both samples' participants reported having no confidence in their knowledge of SLE (70%, sample 1; 50%, sample 2). Participants from both community samples were quite open about having limited knowledge of SLE. Overall, the majority of participants rated closer to the *not confident* end of the scale than towards the *confident* end. Additionally, after completing the questionnaires, participants were asked to compare their knowledge of SLE to the average person. Almost 50% of the second sample reported having the same level of knowledge as an average person. Overall, the second sample showed an increase in having *more knowledge* and *much more knowledge* than the average person and fewer people reported having *less knowledge* and *much less knowledge* than the average person. This may reflect the trustworthiness of sample two over sample one. The age difference between the samples (i.e., an average age of 21.5 in sample 1 compared with an average age of 33 in sample 2) might represent differences in maturity and life experience. These factors, in turn, could have accounted for some of the differences in knowledge. Of course, these hypotheses were not evaluated within the context of this particular study.

Based on the results from the current study the average level of SLE knowledge is quite low. However, since no study has examined SLE knowledge among community members there was previously no known rate of SLE knowledge. Therefore, understanding the perceived level of knowledge and identifying the average LKQ and LKQ-R scores allows for the opportunity to explore and develop advocacy efforts aimed at increasing accurate knowledge. The average persons' knowledge, based on findings from this study and the questionnaires, indicates that knowledge is likely somewhere between 16% and 41%. Even more, participants believed they

had much lower knowledge compared to the average person. Together these indicate that community members are confidently unaware of SLE. This low level of SLE knowledge and perceptions of knowledge among the community is why this area of research is important. Being misinformed about SLE has negative repercussions for the SLE community, such that, being unaware of SLE could likely result in increased stigmatization of patients.

Results of Hypothesis 1

Hypothesis 1 was supported; individuals who reported having educational exposure to SLE scored significantly higher on the LKQ than those who reported no exposure.

Rates of Educational Exposure. For the first community sample, 72% had heard of SLE. However, any deeper level of educational exposure was quite rare with 80% of the sample reporting having never read about SLE. For the second community sample, even more of the sample (95%) had heard of SLE. All other levels of educational exposure were again, quite low. These results indicated that having heard of SLE was quite common; however, reports of having opportunities to learn more about SLE through deeper educational means decreased drastically.

Sample One. During the examination of hypothesis one, the three comparison analyses conducted indicated that there were significant differences among the educational exposure groups. Participants who reported having only heard of SLE were compared to those who reported having a deeper educational experience with SLE. The presumption was that having a deeper learning experience of SLE would mean that a person was able to understand SLE at a deeper level compared to those who had only heard of SLE. The findings of this analysis indicated that having heard of SLE held no significance when it comes to being knowledgeable about the disease mechanism of SLE.

The deeper educational exposure group was compared to those who reported no educational exposure to SLE. Although this may seem like a simple assumption because no study had examined SLE knowledge among community members with a questionnaire there had never been a way to examine the relationship between educational exposure and knowledge. Therefore, although these findings may be viewed as common sense, the examination and findings related to the relationship between educational exposure and LKQ scores were novel. Lastly, those who reported having heard of SLE scored significantly higher on the LKQ than those who reported having no educational exposure to SLE. The result indicates that for this sample having heard of SLE did relate to having higher scores of knowledge when compared to those who reported no educational exposure. However, due to sample one's skewed scores, the result that hearing of SLE is associated with higher knowledge scores should be interpreted with caution. Rather, the findings and conclusions drawn from sample two appear to provide more trustworthy results.

Sample Two. During the examination of hypothesis one for the LKQ-R, the analyses indicated that there was a significant difference among the groups. Further, three comparison examinations were employed to determine what groups scored significantly different than the others. Individuals who reported having a deeper educational exposure to SLE scored significantly higher on the LKQ than those who reported having only heard of SLE. This support of the hypothesis indicates that just having heard of SLE holds no weight when it comes to being knowledgeable about the disease mechanisms of SLE compared to having the opportunity to learn about SLE in a learning environment. Additionally, those who reported having learned about SLE in a deeper educational experience scored significantly higher on the LKQ than those who reported no educational exposure.

Although the finding may seem like common sense the novel analysis and examination of these variables further substantiates the relationship between having educational exposure to SLE and performing better on an SLE knowledge questionnaire. Finally, LKQ scores for individuals who had heard of SLE did not differ significantly from those who reported no educational exposure of SLE. These results indicate is that there seems to be no measurable difference between SLE knowledge of someone who had only heard of SLE versus having no exposure to SLE. These results are different than those from sample one.

The difference between results could be explained by the inability to exclude data from sample one analyses because of not having the validity item. This hypothesis is why the validity item was included in sample two and I propose that the questionnaire design better substantiates sample two's results. Additionally, the differences between the demographics of sample one and sample two likely informed the motivation and effort of the participants' performance on the measures; thus, it is my second hypothesis regarding why the relationship between hearing of SLE and having no educational exposure differed between the two samples.

The implications of having no measurable difference in SLE knowledge scores when having only heard of the illness versus having no educational exposure to SLE is cause for some alarm. The concern lies in the presumption that people who have heard of SLE are likely unknowledgeable (according to these results) about the factual experiences of SLE but because they have some awareness of the illness (i.e., the name) they could be contributing to the societal misconceptions of SLE. If they are reinforcing false notions about SLE these individuals could be perpetuating inaccurate facts as true. Increasing accurate knowledge has the possibility to decrease the negative stigma and misconceptions of SLE that are associated with invisible illnesses, like SLE.

Results of Hypothesis 2

Hypothesis 2 was supported; individuals who report having close proximity to SLE scored significantly higher on the LKQ than those who do not have disease proximity.

Rates of Disease Proximity. Participants who reported having SLE, often times also reported having a family member with SLE. These results are indicative of the genetic nature of SLE (Ramos & Brown, 2010; Sestak et al., 2007; Harley et al., 2006). Some participants even reported knowing someone of every relation (self, immediate, extended and other), which due to genetics and the likelihood of meeting other people with SLE through support groups these results are not surprising.

Sample One. During the examination of hypothesis two of the draft version, results indicated that there was a significant difference among the disease proximity groups. Additional tests were employed to determine where the significant differences existed. Individuals in the close proximity group were compared to those in the other proximity group and the scores indicated no significant difference. The participants who reported having close proximity (self or family) did not score differently than those who reported knowing someone else with SLE. Initially, there is was a presumption that having someone of close relation (e.g., self, immediate and extended family) would have more influence on the participant's knowledge of SLE than knowing someone of other relations. However, the findings indicated that it did not matter what relation the person had to someone with SLE; rather, just knowing someone with SLE influenced participants' SLE knowledge. Someone reporting having an aunt with SLE may mean the same, in terms of the influence of knowledge, for the participant as having a friend with SLE.

Those with close proximity to SLE scored significantly higher on the LKQ compared to those with no proximity. Similarly, those who reported knowing someone else with SLE scored

significantly better on the LKQ than those with no proximity. Therefore, these two results indicated that having some personal relation to a person with SLE results in having significantly better scores on the LKQ. As highlighted during the discussion of hypothesis one, although these findings may seem like a simple assumption because no study has examined SLE knowledge and the effects of disease proximity, this conclusion could not be confirmed. One possible explanation for this could be that knowing someone with SLE provides the participant an opportunity to learn about SLE through the personal experiences of someone diagnosed and/or encourages the participant to educate him or herself on the disease. Of note, there was a statistically significant association between those who identified as having proximity to SLE and those who identified having educational exposure to SLE.

Sample Two. During the examination of hypothesis two for the revised version, the overall analysis indicated that there was a significant difference among the proximity groups. Post hoc tests were employed to determine where the significant differences existed. Although the results from sample one should be taken with caution, the results of hypothesis two for the second sample were identical. Participants who reported having a close proximity did not statistically differ between those who reported knowing someone else with SLE. There seems to be no indication that having a closer relationship (as categorized for this study) holds any significance to resulting in higher knowledge. Those in the close proximity group and those in the other proximity group scored significantly better on the LKQ than those who reported knowing no one with SLE. Both results indicate that having some relation to a person with SLE results in higher scores on the LKQ. It seems that when someone knows a person with SLE they are more inclined or more likely to be exposed to facts or life experiences of SLE and therefore, are more knowledge.

One possible conclusion that could explain both samples' findings, in terms of disease proximity, is that having any relation to someone with SLE results in one being better educated about the disease. It does not seem to differ between the relation that the person holds (close vs. other) but having any proximity to SLE is associated with higher knowledge of SLE compared to someone who knows no one with SLE. Ultimately, there are too many illnesses in our society to be knowledgeable about all of them. Thus, knowing anyone with SLE might serve as an incentive or an opportunity to discuss the disease. There is something important about knowing a person with SLE that makes others more knowledgeable of the disease.

Study Limitations

Although the current studies' hypotheses were supported, the samples utilized were not the typical beginning point of questionnaire development, because they consisted of community members and did not all have a direct relation to SLE. Sample one of the current study consisted of young adults ranging from age 18 to 24 and sample two consisted of parents who ranged from 20 to 54 years old. A major consideration that has been mentioned is that the samples were not ideal and furthermore, the findings from sample one should be taken with caution due to the design flaw with no validity item. The ideal sample that previous researchers have utilized when creating a novel or adapting a disease-specific questionnaire is one that incorporates "knowledgeable participants", this includes: patients, providers and those who work in a setting where they need knowledge of the condition (Jaworski & Carey, 2007; Carey & Schroder, 2002; Bergman et al., 2011; Wagner et al., 2005; White et al., 2006; Giordano et al., 2010; Winzenberg et al., 2003; Edworthy, Devins, & Watson, 1995).

Provided that the samples utilized were not ideal, modifications had to occur when it came to assigning participants to the groups. The participants were asked to report any

educational exposure (heard of, read about, learned in class, attended lecture) and disease proximity (self, immediate, extended family, other) regarding SLE. After responses were tabulated, participants were categorized into only one group for each variable. Still, some participants reported more than one degree of educational exposure or disease proximity. Nevertheless, they were categorized into groups depending on which group they identified with that had the lowest number of participants who also endorsed that item. For example, if someone reported having attended a lecture on SLE and reported hearing about SLE, that person's data were put into the deeper educational group rather than the heard of SLE group. The same occurred for disease proximity, if a participant endorsed having a self-diagnosis of SLE and knowing someone else with SLE, their data was put into the close proximity group. Overall, this grouping system was not ideal; however, since the results supported the hypotheses it may not be as significant of a limitation.

A final limitation of the current study exists because the current study's hypotheses; however, altering the research aims could correct for the limitation. Individuals in both samples were asked whether they had heard of SLE and in both samples some individuals reported not having ever heard of it. For the purpose of the current hypotheses, these participants were valuable. That was the case because I wanted to understand the relationship between all dimensions of educational exposure and disease proximity, including those who identified as having none. However, those participants' data were still included in the item analyses of the LKQ and the LKQ-R. The limitation lies in the issue that by keeping those individuals' data in the final analyses the interpretation of the knowledge questionnaire as a whole includes data from individuals who had never even heard of SLE, which is not informative to understanding what items are indicative of higher knowledge.

Future Directions

Future research designs should be aimed to correct the limitations mentioned for the current study. Further assessments of the LKQ-R should involve increasing the number of participants within each educational exposure and disease proximity group. Although the grouping procedure used provided appropriate participants, the number of participants in the "none" groups (both for disease proximity and educational exposure) were substantially lower than the number of participants in the other two groups in the two variables. Since some participants endorsed more than one item (e.g., I have heard of SLE and I have read about it in a class) there is a chance that a deeper understanding of SLE knowledge was lost because participants' data were not assessed based on more than one endorsement of each variable. Future designs should employ independent groups to ensure that the results can be replicated.

For the current study, assumptions were made regarding which grouping category held more weight; however, it is hard to presume the influence of various educational experiences or the strength of the relationships participants reported on. Therefore, for future examinations adding items to assess the perceived strength of the participants' educational exposure to SLE (i.e., to what degree did you learn about SLE in a class) as well as have a way to assess the strength of the relationship between the participant and the person/people they identify as knowing with SLE (i.e., does an immediate family member represent a stronger relationship vs. extended family vs. knowing someone else) could provide more valuable information. A participant only hearing of SLE on a television show versus having heard of SLE from a patient could indicate a stronger relationship and expand the current understanding of the dimensions that lead to higher knowledge rates (i.e., what is associated with more knowledge). Additionally, a specifier aimed at determining the strength of the relationship that a person indicated when

endorsing the disease proximity items could be informative. For example, a familial relationship may not be conducive of more SLE knowledge; rather, having a close friend diagnosed may be a stronger relationship that is conducive to a participant having more SLE knowledge.

This study was the first step in a broader research agenda designed to continue to understand the influence of SLE knowledge. As the first step, the aim was to create a questionnaire and conduct preliminary analyses to explore community members' knowledge. The next step should be to assess the utility of this measure in patient and provider samples. Those are the samples that are theoretically presumed to have more knowledge of the disease and thus, these samples would be the typical starting point (Reeve et al., 2013). Utilizing patients and gathering psychometric data on the measure within this sample will allow for the future use of the LKQ-R as an additional measure within protocols of patient education research. With further use and examinations of the LKQ-R, it is the hope that it will become a common measure that future researchers can use to assess the influence of SLE knowledge in various research designs. Similarly, utilizing a provider sample will allow for the LKQ-R to be aimed at examining the rates of knowledge that providers have of SLE and where gaps exist. New interventions can be aimed to increase medical providers' knowledge.

A final consideration is that the scope of the current study did not fully address all results gathered. In fact, more data was gathered that could be examined to address alternate hypotheses, including ones regarding what content areas of knowledge are scored at higher rates or which various items on the LKQ-R are scores correctly more often than others. Understanding details regarding which items are scored correctly more often could inform our considerations of what knowledge themes are more well-known, which would be more novel insights. For instance,

understanding what categories of disease proximity and educational exposure could have related to a higher correct rate of individual items or the overall scale score.

Contribution to the Literature

Although some limitations exist, the findings from this study have provided a novel and monumental method of exploring the dimension of SLE knowledge. As mentioned previously, no measure like the LKQ-R exists; therefore, the creation of the LKQ-R is a novel contribution to the field. The results from the assessment of the LKQ and the LKQ-R within the two community samples provide the first examination of disease-specific knowledge and the effects of education and proximity. The findings support the notion that educational experience and disease proximity contribute to SLE knowledge, which are novel scientific contributions.

Clinical Implications

After continued testing within patient and provider samples, it is my hope that the LKQ-R will become a commonly utilized measurement tool to assess SLE knowledge in a systematic way. The questionnaire could be used by providers to educate newly diagnosed patients. Patients report being unsatisfied with the information that their providers give them after receiving a diagnosis (Waldron et al., 2011). Therefore, having a tool like the LKQ-R could be used to assess facts that are known and unknown among new patients. This tool could be used in the medical settings to gather knowledge data at diagnosis and continue to gather follow-up knowledge data. Additionally, this could help providers see what dimensions of SLE knowledge (cause, timeline, etc.) patients are less knowledgeable of and provide them with additional educational material on that specific domain. These findings extend the field by allowing clinicians to be able to educate their patients on the reality SLE has on one's health.

For patients, the future use of the LKQ-R could be used within educational interventions. Previous researchers have identified the success of behavioral changes that occur when a component of disease-specific information is examined (Cunningham & Kashikar-Zuck, 2013; Brown et al., 2012; Ramos-Remus et al., 2000). There had been no systematic way to assess the knowledge of SLE, instead, authors created their own assessment variables to examine knowledge (Konttinen et al.,1991; Young et al., 2002). The LKQ-R could become an essential measurement tool for future SLE interventions research studies that want to assess disease knowledge as a variable. Interventions that incorporate an educational aspect of disease have shown significant improvements for patients' mental and physical health experiences (Keefe, 1996; Keefe, Somers, & Martire, 2008; Evers et al., 2002; Rinaldi et al., 2006; Haupt et al., 2005). Findings from these previous research studies provide support that with a tool like the LKQ-R future interventions can become stronger by examining disease knowledge.

Conclusion

The first ever global assessment of SLE awareness was just released to the public in May of 2016. The World Lupus Federation conducted a study across 16 countries with 16,911 participants to determine the public's awareness and attitudes about SLE (Lupus Foundation of America, 2016). The global assessment found that 36% of the participants did not know SLE was a disease and 51% did not know that SLE results in severe health complications. The survey also found that the misconception surrounding SLE are increasingly believed across the world. Knowing that the global misconceptions of SLE are potentially worse than imagined assessing accurate rates of knowledge and improving knowledge is a goal to correct the misconceptions.

The results of this study provided the foundational work that informs a research agenda aimed at utilizing the LKQ as a novel assessment tool in SLE research. Through the four

developmental phases, there was evidence that the LKQ-R is backed by medical information and has the capabilities to identify levels of knowledge participants have of SLE based on their education exposure and disease proximity. By creating the LKQ and LKQ-R the first examination of community members' knowledge of SLE was conducted. Furthermore, assessing knowledge perceptions provided an additional novel finding related to whether participants have actual knowledge or just perceive to have knowledge. Understanding what factors influence community members' knowledge is the first step in creating feasible and informative educational interventions aimed to increase SLE awareness and decrease the false stigma associated with SLE.

References

American Autoimmune Related Diseases Association (2011). The Cost Burden of Autoimmune Disease: The Latest Front in the War on Healthcare Spending. Retrieved from www.aarda.org/pdf/cbad.pdf?

Bachen, E. A., Chesney, M. A., & Criswell, L. A. (2009). Prevalence of mood and anxiety disorders in women with systemic lupus erythematosus. *Arthritis Care & Research*, 61(6), 822-829.

Beatty, P. & Herrmann. D. (1995). A framework for evaluating "don't know" responses in Surveys. National Center for Health Statistics, 1005–1010. Retrieved from http://medcontent.metapress.com/index/A65RM03P4874243N.pdf

Beck, C. T., & Gable, R. K. (2001). Ensuring content validity: An illustration of the process. *Journal of Nursing Measurement, 9,* 201–215.

Beckerman, N. L., Auerbach, C., & Blanco, I. (2011). Psychosocial dimensions of SLE: implications for the health care team. *Journal of Multidisciplinary Healthcare*, *4*, 63–72. doi: 10.2147/JMDH.S19303

Bennett, J. K., Fuertes, J. N., Keitel, M., & Phillips, R. (2011). The role of patient attachment and working alliance on patient adherence, satisfaction, and health-related quality of life in lupus treatment. *Patient Education and Counseling*, *85*(1), 53–59. doi: 10.1016/j.pec.2010.08.005

Benseler, S. M., & Silverman, E. D. (2007). Systemic lupus erythematosus. *Rheum Dis Clin North Am*, *33*(3), 471–98. doi:10.1016/j.rdc.2007.07.008

Bergman, H. E., Reeve, B. B., Moser, R. P., Scholl, S., & Klein, W. M. P. (2011). Development of a comprehensive heart disease knowledge questionnaire. *American Journal of Health Education, 42*(2), 74–87. doi:10.1080/19325037.2011.10599175

Brennan, K. A., & Creaven, A. M. (2015). Living with invisible illness: Social support experiences of individuals with systemic lupus erythematosus. *Quality of Life Research,* Oct, e1-e9. doi: 10.1007/s11136-015-1151-z

Brown, R. T., Shaftman, S. R., Tilley, B. C., Anthony, K. K., Kral, M. C., Maxson, B.,…Nietert, P. J. (2012). The health education for lupus patients study: A randomized controlled cognitive-behavioral intervention targeting psychosocial adjustment and quality of life in adolescent females with systemic lupus erythematosus. *American Journal of Medical Science, 344(4),* 274-282. doi:10.1097/MAJ.0b013e3182449be9

Carder, P. C., Vuckovic, N., & Green, C. A. (2003). Negotiating medications: Patient perceptions of long-term medication use. *Journal of Clinical Pharmacy and Therapeutics*, *28*, 409–417. doi: 10.1046/j.0269-4727.2003.00511.x

Calderon, J. L., Morales, L. S., Liu, H., & Hays, R. D. (2006). Variation in the readability of items within surveys. *American Journal of Medicine, 21*(1), 49-56.

Cameron, L. D. (2003, February). Conceptualizing and assessing risk perceptions "A self-regulatory perspective. Presentation at the Conceptualizing and Measuring Risk Perceptions Workshop, Washington, D.C.

Carey, M. P., & Schroder, K. E. E. (2002). Development and psychometric evaluation of the brief HIV knowledge questionnaire. *AIDS Education and Prevention*, *14*(2), 172–182. doi:10.1521/aeap.14.2.172.23902

Carpenter, B. D., Balsis, S., Otilingam, P. G., Hanson, P. K., & Gatz, M. (2009). The alzheimer's disease knowledge scale: Development and psychometric properties. *The Gerontologist*, *49*(2), 236–247. doi: 10.1093/geront/gnp023

Chatham, W. W. & Kimberly, R. P. (2001). Treatment of lupus with corticosteroids. *Lupus, 10,* 140-147. doi: 10.1191/096120301675075008

Chambers, S. A., Raine, R., Rahman, A., & Isenberg, D. (2009). Why do patients with systemic lupus erythematosus take or fail to take their prescribed medications? A qualitative study in a UK cohort. *Rheumatology*, *48,* 266–271. doi:10.1093/rheumatology/ken479

Chan, Y., & Walmsley, R. P. (1997). Learning and understanding the kruskal-wallis one-way analysis-of variance-by-ranks test for differences among three or more independent groups. *Physical Therapy, 77*(12), 1755-1761.

Clark, A. L., & Watson, D. (1995). Constructing validity: Basic issues in objective scale development. *Psychological Association September*, *7*(3), 309–319.

Clowse, M. E. B., Magder, L. S., Witter, F., & Petri, M. (2005). The impact of increased lupus activity on obstetric outcomes. *Arthritis & Rheumatism*, *52*(2), 514–521. doi:10.1002/art.20864

Coleman, C. I., Limone, B., Sobieraj, D. M., Lee, S., Roberts, M. S., Kaur, R., & Alam, T. (2012). Dosing frequency and medication adherence in chronic disease. *Journal of Managed Care Pharmacy, 18*(7), 527–39.

Coleman, M., & Liau, T. L. (1975). A computer readability formula designed for machine scoring. *Journal of Applied Psychology*, *60*(2), 283–284. doi: 10.1037/h0076540

Cojocaru, M., Cojocaru, I. M., Silosi, I., & Vrabie, C. D. (2011). Manifestations of systemic lupus erythematosus. *Medical, 6(4),* 330–336. doi: 10.1155/2012/834291

Collins, G. S., Mughal, S., Barnett, A. H., Fitzgerald, J., & Lloyd, C. E. (2010). Modification and validation of the revised diabetes knowledge scale. *Diabetic Medicine, 28,* 301-310. doi:10.1111/j.1464-5491.2010.03190.x

Costedoat-Chalumeau, N., Pouchot, J., Guettrot-Imbert, G., Le Guern, V., Leroux, G., Marra, D., … Piette, J. C. (2013). Adherence to treatment in systemic lupus erythematosus patients. *Best Practice & Research Clinical Rheumatology, 27(3),* 329–40. doi: 10.1016/j.berh.2013.07.001

Crampton, S. P., Morawski, P. A., & Bolland, S. (2014). Linking susceptibility genes and pathogenesis mechanisms using mouse models of systemic lupus erythematosus. *Disease Models & Mechanisms*, *7*(9), 1033–1046. doi: 10.1242/dmm.016451

Crocker, L. & Algina, A. (1986). Introduction to classical and modern test theory. New York: Holt, Reinhart, & Winston.

Cunningham, N. R. & Kashikar-Zuck, S. (2013). Nonpharacologic treatment of pain in rheumatic diseases and other musculoskeletal pain conditions. *Current Rheumatology Report, 15*(2), 306-320. doi:10.1007/s11926-012-0306-y

Danoff-Burg, S., & Friedberg, F. (2009). Unmet needs of patients with systemic lupus erythematosus. *Behavioral Medicine*, *35*(1), 5–13. doi:10.3200/BMED.35.1.5-13

Davis, L. L. (1992). Instrument review: Getting the most from a panel of experts. *Applied Nursing Research, 5,* 194-197.

Denniston, A. K., Kyte, D., Calvert, M., & Burr, J. M. (2014). An introduction to patient-reported outcome measures in ophthalmic research. *Eye, 28(6),* 1–9. doi: 10.1038/eye.2014.41

DeVellis, R.F. (2003). Scale development: Theory and applications. 2nd Ed. Newbury Park, CA: Sage Publications.

DeVon, H. A., Block, M. E., Moyle-Wright, P., Ernst, D. M., Hayden, S. J., Lazzara, D. J., … Kostas-Polston, E. (2007). A psychometric toolbox for testing validity and reliability. *Journal of Nursing Scholarship*, *39*(2), 155–164. doi: 10.1111/j.1547-5069.2007.00161.x

Diefenbach, M. A. & Leventhal, H. (1996). The common-sense model of illness representations: Theoretical and practical considerations. *Journal of Social Distress and the Homeless, 5(1),* 11-38.

Dobkin, P. L., Da Costa, D., Dritsa, M., Fortin, P. R., Senécal, J. L., Goulet, J. R., … Clarke, A. E. (1999). Quality of life in systemic lupus erythematosus patients during more and less active disease states: Differential contributors to mental and physical health. *Arthritis Care and Research*, *12(6)*, 401–410.

Dobkin, P. L., Fortin, P. R., Joseph, L., Esdaile, J. M., Danoff, D. S., & Clarke, A. E. (1998). Psychosocial contributors to mental and physical health in patients with systemic lupus erythematosus. *Arthritis Care and Research, 11(1)*, 23–31.

Durán, S., Apte, M., & Alarcón, G. S. (2007). Poverty, not ethnicity, accounts for the differential mortality rates among lupus patients of various ethnic groups. *Journal of the National Medical Association*, *99*(10), 1196–1198.

Earnshaw, V. A., Quinn, D. M., & Park, C. L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness, 8(2),* 79-88. doi: 10.1177/1742395311429393

Edworthy, S. M., Devins, G. M., & Watson, M. M. (1995). The arthritis knowledge questionnaire. A test for measuring patient knowledge of arthritis and its self-management. *Arthritis and Rheumatism*, *38*(5), 590–600. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/7748213

Evers, A. W. M., Kraaimaat, F. W., Van Riel, P. L. C. M., & De Jong, A. J. L. (2002). Tailored cognitive-behavioral therapy in early rheumatoid arthritis for patients at risk: A randomized controlled trial. *Pain*, *100*, 141–153. doi: 10.1016/S0304-3959(02)00274-9

Feldman, C. H., Hiraki, L. T., Liu, J., Fischer, M. A., Solomon, D. H., Alarcõn, G. S., … Costenbader, K. H. (2013). Epidemiology and sociodemographics of systemic lupus erythematosus and lupus nephritis among US adults with Medicaid coverage, 2000-2004. *Arthritis and Rheumatism*, *65*(3), 753–763. doi:10.1002/art.37795

Fitzgerald, J. T., Funnell, M. M., Hess, G. E., Barr, P. A., Anderson, R. M., Hiss, R. G., & Davis, W. K. (1998). The reliability and validity of a brief diabetes knowledge test. *Diabetes Care*, *21*(5), 706–710. doi:10.2337/diacare.21.5.706

Freire, E. L. S., & Ciconelli, R. (2011). Assessment measures in systemic lupus erythematosus. *Revista Brasileira de Reumatologia*, *51*(1), 70–80.

Friedman, D.B., & Hoffman-Goetz, L. (2006). A systematic review of readability and comprehension instruments used for print and web-based cancer information. *Health Education & Behavior*, *33*(3), 352–373. doi: 10.1177/1090198105277329

Ghasemi, A., & Zahediasl, S. (2012). Normality tests for statistical analysis: A guide for non-statisticians. *International Journal of Endocrinology and Metabolism*, *10*(2), 486–489. doi:10.5812/ijem.3505

Giffords, E. D. (2003). Understanding and managing systemic lupus erythematosus (SLE), *Social Work in Health Care, 37(4),* 57-72, DOI: 10.1300/J010v37n04_04

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: Interviews and focus groups. *British Dental Journal*, *204(6)*, 291–295. doi: 10.1038/bdj.2008.19

Giordano, A., Messmer-Uccelli, M., Pucci, E., Martinelli, V., Borreani, C., Lugaresi, A., … Solari, A. (2010). The multiple sclerosis knowledge questionnaire: A self-administered instrument for

recently diagnosed patients. *Multiple Sclerosis Journal*, *16*(1), 100–111. doi:10.1177/1352458509352865

Hagger, M. S. & Orbell, S. (2003). A meta-analysis review of the common-sense model of illness representations. *Psychology and Health, 18(2),* 141-184. doi: 10.1080/088704403100081321

Hale, E.D., Treharne, G.J., & Kitas, G.D. (2007). The common-sense model of self-regulation of health and illness: How can we use it to understand and respond to patients' needs? *Rhumatology, 46*, 904-906. doi:10.1093/rheumatology/kem060

Hale, E. D., Treharne, G. J., Lyons, A. C., Norton, Y., Mole, S., Mitton, D. L., … Kitas, G. D. (2006). "Joining the dots" for patients with systemic lupus erythematosus: Personal perspectives of health care from a qualitative study. *Annals of the Rheumatic Diseases*, *65*, 585–589. doi: 10.1136/ard.2005.037077

Harley, J.B., Kelly, J.A., & Kaufman, K.M. (2006). Unraveling the genetics of systemic lupus erythematosus. *Springer Seminars in Immunopathology, 28(2),* 119-130. doi:10.1007/s00281-006-0040-5

Harrold, L. R., & Andrade, S. E. (2009). Medication adherence of patients with selected rheumatic conditions: A systematic review of the literature. *Seminars in Arthritis and Rheumatism*, *38*(5), 396–402. doi: 10.1016/j.semarthrit.2008.01.011

Haupt, M., Millen, S., Jänner, M., Falagan, D., Fischer-Betz, R., & Schneider, M. (2005). Improvement of coping abilities in patients with systemic lupus erythematosus: a prospective study. *Annals of the Rheumatic Diseases*, *64*(11), 1618–1623. doi: 10.1136/ard.2004.029926

Helmick, C.G., Felson, D.T., Lawrence, R.C., Gabriel, S., Hirsch, R., Kwoh, C.K…Stone, J.H. (2008). Estimates of the prevalence of arthritis and other rheumatic conditions in the united states. *Arthritis & Rheumatism, 58(1),* 15-25. doi: 10.1002/art/23177

Hennell, S. L., Brownsell, C., & Dawson, J. K. (2004). Development, validation and use of a patient knowledge questionnaire (PKQ) for patients with early rheumatoid arthritis. *Rheumatology, 43*(4), 467–71. doi:10.1093/rheumatology/keh069

Hochberg, M. C. (1997). Updating the american college of rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis & Rheumatism*, *40*(9), 1725. doi:10.1002/1529-0131(199709)40:9

Holloway, L., Humphrey, L., Heron, L., Pilling, C., Kitchen, H., Hojbjerre, L.,…Hansen, B.B. (2014). Patient-reported outcome measures for systemic lupus erythematosus clinical trials: A review of content validity, face validity and psychometric performance. *Health and Quality of Life Outcomes, 12*,116-130.

Hsieh, H.F. & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. doi: 10.1177/1049732305276687

IBM Corp. Released 2010. IBM SPSS Statistics for Windows, Version 19.0. Armonk, NY: IBM Corp

Jaglarz, K., Tomaszewski, K. A., Kamzol, W., Puskulluoglu, M., & Krzemieniecki, K. (2014). Creating and field-testing the questionnaire for the assessment of knowledge about cervical cancer and its prevention among schoolgirls and female students. *Journal of Gynecologic Oncology, 25(2),* 81–89. doi: 10.3802/jgo.2014.25.2.81

Jaworski, B. C., & Carey, M. P. (2007). Development and psychometric evaluation of a self-administered questionnaire to measure knowledge of sexually transmitted diseases. AIDS and behavior, 11, 557-574.

Johnson, C., Aaronson, N., Blazeby, J. M., Bottomley, A., Fayers, P., Koller, M., … Young, T. (2011). Guidelines for Developing Questionnaire Modules Quality of Life Group. *EORTC Quality of Life Group*, (April).

Julian, L.J., Yelin, E., Yazdany, J., Panopalis, P., Trupin, L., Criswell, L.A., & Katz, P. (2009). Depression, medication adherence, and service utilization in systemic lupus erythematosus. *Arthritis & Rheumatology, 61(2),* 240-246. doi: 10.1002/art.24236

Karlson, E.W., Liang, M.H., Eaton, H., Huang, J., Fitzgerald, L., Rogers, M.P., & Daltroy, L.H. (2004). A randomized clinical trial of a psychoeducational intervention to improve outcomes in systemic lupus erythematosus. *Arthritis and Rheumatism*, *50*(6), 1832–1841. http://doi.org/10.1002/art.20279

Keefe, F. J. (1996). Cognitive behavioral therapy for managing pain. *The Clinical Psychologist*, *49*, 4-5.

Keefe, F. J., Somers, T. J., & Martire, L. M. (2008). Psychologic interventions and lifestyle modifications for arthritis pain management. *Rheumatic Diseases Clinics of North America*, *34*(2), 351–368. doi:10.1016/j.rdc.2008.03.001

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K.R., & Walters, E.E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. *Arch Gen Psychiatry*, *62(6),* 593–602. doi: 10.1001/archpsyc.62.6.593

Kincaid, J.P., Fishburne, R.P., Rogers, R.L., & Chissom, B.S. (1975). Derivation of new readability formulas (automated readability index, fog count and flesch reading ease formula) for navy enlisted personnel. *Technical Training*, *Research*(February), 49.

Konttinen, Y. T., Santavirta, N., Honkanen, V., Sandelin, S., & Schauman, L. (1991). Systemic lupus erythematosus patient guide: influence on knowledge of the disease. *Annals of the Rheumatic Diseases, 50*, 900–902. doi:10.1136/ard.50.12.900

Kool, M. B., & Geenen, R. (2012). Loneliness in patients with rheumatic diseases: The significance of invalidation and lack of social support. *The Journal of Psychology*, *146*, 229–241. doi:10.1080/00223980.2011.606434

Kool, M. B., van Middendorp, H., Lumley, M.A., Schenk, Y., Jacobs, J.W.G., Bijlsma, J.W.J., & Geenen, R. (2010). Lack of understanding in fibromyalgia and rheumatoid arthritis: The Illness invalidation inventory (3*I). *Annals of the Rheumatic Diseases*, *69*, 1990–1995. doi: 10.1136/ard.2009.123224

Kozora, E., Ellison, M. C., & West, S. (2006). Depression, fatigue, and pain in systemic lupus erythematosus (sle): Relationship to the american college of rheumatology sle neuropsychological battery. *Arthritis Care and Research*, *55*(4), 628–635. doi:10.1002/art.22101

Lam, G. K. W. & Petri, M. (2005). Assessment of systemic lupus erythematosus. *Clinical and Experimental Rheumatology*, *23*(8), S120 – S130.

Lau, C.S. & Mak, A. (2009). The socioeconomic burden of SLE. *National Review of Rheumatology, 5,* 400-404. doi:10.1038/nrrheum.2009.10 6

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense model of illness danger. In: Rachman,S. (Ed.s), Medical Psychology, 2, pp. 7-30. Pergamon, New York.

Lupus Foundation of America. (n.d.). Retrieved December 12, 2015, from http://www.lupus.org/about/statistics-on-lupus

Lupus Foundation of America. (2016, May). New Global Survey Reveals Most People Have Serious Misconceptions about Lupus. Retrieved on May 20,2016, from http://www.lupus.org/general-news/entry/global-survey-reveals-serious-misconceptions-about-lupus

Lynn, M. R. (1986). Determination and quantification of content validity. *Nursing Research, 35,* 382-385.

Marengo, M., Waimann, C., Achaval, S., Zhang, H., Garcia-Gonzalez, A., Richardson, M., Reveille, J., & Suarez-Almazor, M. (2012). Measuring therapeutic adherence in systemic lupus

erythematosus with electronic monitoring. *Lupus, 21,* 1158-1165. doi: 10.1177/0961203312447868

Mak, A., Ho, R. C. M., & Lau, C. S. (2009). Clinical implications of neuropsychiatric systemic lupus erythematosus. *Advances in Psychiatric Treatment*, *15*, 451–458. doi: 10.1192/apt.bp.108.005785

McCowan, R.J. & McCowan, S.C. (1999). Item Analysis for Criterion-Referenced Tests. Center for Development of Human Services: Buffalo, New York.

McElhone, K., Abbott, J., Shelmerdine, J., Bruce, I. N., Ahmad, Y., Gordon, C., … Teh, L. (2007). Development and validation of a disease-specific health-related quality of life measure, the LupusQol, for adults with systemic lupus erythematosus. *Arthritis & Rheumatism*, *57*(6), 972–979. doi:10.1002/art.22881

Meszaros, Z.S., Perl, A., & Faraone, S.V. (2012). Psychiatric symptoms in systemic lupus erythematosus. *The Journal of Clinical Psychiatry*, *73*, 993–1001. doi: 10.4088/JCP.11r07425

Moses, N., Wiggers, J., Nicholas, C., & Cockburn, J. (2005). Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus. *Patient Education and Counseling*, *57*(*1),* 30–38. doi:10.1016/j.pec.2004.03.015

Nery, F. G., Borba, E. F., Hatch, J. P., Soares, J. C., Bonfá, E., & Neto, F. L. (2007). Major depressive disorder and disease activity in systemic lupus erythematosus. *Comprehensive Psychiatry*, *48*(1), 14–19. doi:10.1016/j.comppsych.2006.04.002

Nery, F. G., Borba, E. F., Viana, V. S. T., Hatch, J. P., Soares, J. C., Bonfá, E., & Neto, F. L. (2008). Prevalence of depressive and anxiety disorders in systemic lupus erythematosus and their association with anti-ribosomal P antibodies. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, *32*(3), 695–700. doi:10.1016/j.pnpbp.2007.11.014

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). 2006. Lupus: A patient care guide for nurses and other health professionals. U.S. Department of Health and Human Services.

Ottonello, M. (2007). Cognitive-behavioral interventions in rheumatic diseases. *Giornale Italiano Di Medicina Del Lavoro Ed Ergonomia*, *29*(1), A19–23. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/17650738

Parker, J.C., Frank, R.G., Beck, N.C., Smarr, K.L., Buescher, K.L., Phillips, L.R., … Walker, S.E. (1988). Pain management in rheumatoid arthritis patients. A cognitive-behavioral approach. *Arthritis and Rheumatism*, *31*(5), 593–601.

Parrondo, R. R. (2011). Integral treatment of systemic lupus erythematosus, challenges in rheumatology, Dr. Miroslav Harjacek (Ed.), ISBN: 978-953-307-848-9, InTech, Available from: http://www.intechopen.com/books/challenges-in-rheumatology/integral-treatment-of-systemic-lupus-erythematosus

Panopalis, P., & Clarke, A. E. (2006). Quality of life in systemic lupus erythematosus. *Clinical and Developmental Immunology*, *13*(2-4), 321–324. doi:10.1080/17402520600877760

Patton, M. (1990). Qualitative evaluation and research methods. *Qualitative Evaluation and Research Methods*, 169–186. doi: 10.1002/nur.4770140111

Pego-Reigosa, J.M., & Isenberg, D.A. (2008). Psychosis due to systemic lupus erythematosus: Characteristics and long-term outcome of this rare manifestation of the disease. *Rheumatology*, *47*(10), 1498–1502. doi: 10.1093/rheumatology/ken260

Poe, G.S., Seeman, I., Mclaughlin, J., Mehl, E., & Dietz, M. (1988). “Don’t know” boxes in factual questions in a mail questionnaire effects on level and quality of response. *The Pubic Opinion Quarterly*, *52*(2), 212–222.

Polit, D.F. & Beck, C.T. (2006). The content validity index: Are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health*, *29*, 489-497. doi:10.1002/nur.20147

Polit, D.F. & Beck, Owen, S.V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health, 30*(4), 459-467. doi: 10.1002/nur.2019

Pons-Estel, G. J., Alarcón, G. S., Scofield, L., Reinlib, L., & Cooper, G. S. (2010). Understanding the epidemiology and progression of systemic lupus erythematosus. *Seminars in Arthritis and Rheumatism*, *39*(4), 257–268. doi:10.1016/j.semarthrit.2008.10.007

Potter, W. J., & Levine-Donnerstein, D. (1999). Rethinking validity and reliability in content analysis. *Journal of Applied Communication Research, 27*, 258-284.

Ramos, P., & Brown, E. (2010). Genetic factors predisposing to systemic lupus erythematosus and lupus nephritis. *Seminars in Nephrology*, *30*(2), 164–176. doi:10.1016/j.semnephrol.2010.01.007.Genetic

Ramos-Remus, C., Salcedo-Rocha, A.L., Prieto-Parra, R.E., & Galvan-Villegas, F. (2000). How important is patient education? *Best Practice and Research: Clinical Rheumatology*, *14*(4), 689–703. doi: 10.1053/berh.2000.0107

Reeve, B. B., Wyrwich, K. W., Wu, A. W., Velikova, G., Terwee, C. B., Snyder, C. F., … Butt, Z. (2013). ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. *Quality of Life Research*, *22*, 1889–1905. doi: 10.1007/s11136-012-0344-y

Rhee, R.L., Von Feldt, J.M., Schumacher, H.R., & Merkel, P.A. (2013). Readability and suitability assessment of patient education materials in rheumatic diseases. *Arthritis Care & Research*, *65*(10), 1702-1706. Doi: 10.1002/acr.22046

Rinaldi, S., Ghisi, M., Iaccarino, L., Zampieri, S., Ghirardello, A., Sarzi-Puttini, P., … Doria, A. (2006). Influence of coping skills on health-related quality of life in patients with systemic lupus erythematosus. *Arthritis and Rheumatism*, *55*(3), 427–433. doi: 10.1002/art.21993

Rudd, R.R., Moeykens, B.A., & Colton, T.C. (1999). Health and literacy: A review of the medical and public health literature, chapter 5. *Annual Review of Adult Learning and Literacy*, *1*, 1–37.

Sestak, A.L., Nath, S.K., Sawalha, A.H., & Harley, J.B. (2007). Current status of lupus genetics. *Arthritis Research & Therapy*, *9(3),* 210-219. doi: 10.1186/ar2176

Sharpe, L. (2003). Long-term efficacy of a cognitive behavioural treatment from a randomized controlled trial for patients recently diagnosed with rheumatoid arthritis. *Rheumatology*, *42*(3), 435–441. doi: 10.1093/rheumatology/keg144

Siklosi, K.R., Gallagher, C.G., & McKone, E.F. (2010). Development, validation, and implementation of a questionnaire assessing disease knowledge and understanding in adult cystic fibrosis patients. *Journal of Cystic Fibrosis*, *9*(6), 400–405. doi:10.1016/j.jcf.2010.07.001

Sim, S.M., & Rasiah, R.I. (2006). Relationship between item difficulty and discrimination indices in true/false-type multiple choice questions of a para-clinical multidisciplinary paper. *Annals of the Academy of Medicine Singapore*, *35*(2), 67–71.

Somers, E.C., Marder, W., Cagnoli, P., Lewis, E.E., DeGuire, P., Gordon, C., … McCune, W.J. (2014). Population-based incidence and prevalence of systemic lupus erythematosus: The michigan lupus epidemiology and surveillance program. *Arthritis & Rheumatology*, *66*(2), 369–378. doi: 10.1002/art.38238

Suda, A. L., Jennings, F., Bueno, V. C., & Natour, J. (2012). Development and validation of fibromyalgia knowledge questionnaire: Fkq. *Rheumatology International*, *32*(3), 655–662. doi:10.1007/s00296-010-1627-7

Sutanto, B., Singh-Grewal, D., McNeil, H. P., O'Neill, S., Craig, J. C., Jones, J., & Tong, A. (2013). Experiences and perspectives of adults living with systemic lupus erythematosus: Thematic synthesis of qualitative studies. *Arthritis Care and Research*, *65*(11), 1752–1765. doi: 10.1002/acr.22032

Stojanovich, L., Zandman-Goddard, G., Pavlovich, S., & Sikanich, N. (2007). Psychiatric manifestations in systemic lupus erythematosus. *Autoimmunity Reviews*, *6*(6), 421–426. doi:10.1016/j.autrev.2007.02.007

Terwee, C.B., Bot, S.D.M., de Boer, M.R., van der Windt, D.A.W.M., Knol, D.L., Dekker, J., … de Vet, H.C.W. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology*, *60*(1), 34–42. doi: 10.1016/j.jclinepi.2006.03.012

Thumboo, J., & Strand, V. (2007). Health-related quality of life in patients with systemic lupus erythematosus: An update. *Annals of the Academy of Medicine Singapore*, *36*(2), 115–122.

Wagner, J., Lacey, K., Chyun, D., & Abbott, G. (2005). Development of a questionnaire to measure heart disease risk knowledge in people with diabetes: The heart disease fact questionnaire. *Patient Education and Counseling*, *58*(1), 82–87. doi:10.1016/j.pec.2004.07.004

Waldron, N., Brown, S., Hewlett, S., Elliott, B., McHugh, N., & McCabe, C. (2011). "It"s more scary not to know': A qualitative study exploring the information needs of patients with systemic lupus erythematosus at the time of diagnosis. *Musculoskeletal Care*, *9*(4), 228–238. doi: 10.1002/msc.221

Ward, B.W., Schiller, J.S., & Goodman, R.A. (2014) Multiple chronic conditions among US adults: a 2012 update. *Prevention of Chronic Disease,* 11:130389. doi: dx.doi.org/10,5888/pcd11.130389

Wheelwright, S., Darlington, A.S., Fitzsimmons, D., Fayers, P., Arraras, J. I., Bonnetain, F., … Johnson, C. (2013). International validation of the EORTC QLQ-ELD14 questionnaire for assessment of health-related quality of life elderly patients with cancer. *British Journal of Cancer*, *109* (July), 852–858. doi:10.1038/bjc.2013.407

White, R., Walker, P., Roberts, S., Kalisky, S., & White, P. (2006). Bristol copd knowledge questionnaire (bckq): Testing what we teach patients about copd. *Chronic Respiratory Disease*, *3*, 123–131. doi:10.1191/1479972306cd117oa

Williams, E.M., Karmen, D., Penfield, M., & Oates, J.C. (2014) Stress intervention and disease in african american lupus patients: The balancing lupus experiences with stress strategies (bless) study. *Health, 6(1),* 71-79. doi: 10.4236/health.2014.61011

Williams, A., Manias, E., & Walker, R. (2008). Interventions to improve medication adherence in people with multiple chronic conditions: A systematic review. *Journal of Advanced Nursing*, *63*, 132–143. doi: 10.1111/j.1365-2648.2008.04656.x

Winzenberg, T.A., Oldernburg, B., Frendin, S., & Jones, G. (2003). The design of a valid and reliable questionnaire to measure osteoporosis knowledge in women: The osteoporosis knowledge assessment tool. *BMS Musculoskeletal Disorders, 4(17),* retrieved from http://www.biomedcentral.com/1471-2474/4/17

Wollack, J. (n.d.). Item Analysis. Retrieved September 4, 2015, from http://www.son.wisc.edu/net/wistrec/net/ItemAnalysisText.htm

Yazdany, J. (2011) Health-related quality of life measurement in systemic lupus erythematosus: The lupusqol, sleqol, and l-qol. *Arthritis Care & Research, 63(11),* S413-S419. doi:10.1002/acr.20636.

Young, S. P., Henderson, E., Cheseldine, D. L., Wilson, a S., Skan, J., Heaton, S., … Gordon, C. (2002). Development and assessment of a world wide web site for systemic lupus erythematosus patient information. *Lupus*, *11*, 478–484. doi:10.1191/0961203302lu225oa

Zhang, J., Wei, W., & Wang, C. (2012). Effects of psychological interventions for patients with systemic lupus erythematosus: a systematic review and meta-analysis. *Lupus*, *21*, 1077–1087. doi:10.1177/0961203312447667

Table 1. Frequency of demographic variables Draft LKQ

Variable		N	Valid Percentage
Gender			
	Female	192	58
	Male	136	41.1
Marital Status			
	Single, never married	295	88.1
	Married	36	10.7
	Divorced	3	.9
Race/Ethnicity			
	White	278	83
	African American	13	3.9
	Asian	4	1.2
	Latino/a	17	5.1
	Mixed Race	18	5.4
	Pacific Islander	1	.3
	Native American	4	1.2
Age			
	18	21	6.6
	19	31	9.8
	20	35	11.1
	21	65	20.6
	22	59	18.7
	23	42	13.3
	24	63	19.9
Current Student Enrollment			
	High School	14	4.2
	Part-time College	21	6.3
	Full-time College	165	49.1

Table 2. Disease Proximity for Sample One

Have you been diagnosed with lupus?	Frequency	Percent	Valid Percent
Yes	3	0.9	0.9
No	328	96.7	99.1
Prefer not to answer	8	2.4	
Total	336		

Do you have an immediate family member with lupus?	Frequency	Percent	Valid Percent
Yes	8	2.4	2.4
No	319	94.9	97.6
Prefer not to answer	9	2.7	
Total	336		

Do you have an extended family member with lupus?	Frequency	Percent	Valid Percent
Yes	14	4.2	4.3
No	311	92.6	95.7
Prefer not to answer	11	3.3	
Total	336		

Do you know anyone else with lupus?	Frequency	Percent	Valid Percent
Yes	34	10.1	10.4
No	293	87.2	89.6
Prefer not to answer	9	2.7	
Total	336		

Table 3. Description of "Yes"

Immediate Family	**Frequency**
Grandmother	1
In-Law	1
Sister	1
Mother	3
Parent	1
Omitted	1
Extended Family	**Frequency**
Aunt	7
Cousin	3
First Cousin	1
Second Cousin	3
Other	**Frequency**
Friend	10
Former (colleague, friend, roommate)	4
Neighbor	2
Friends' parent	2
Acquaintance	2
Family friend	1
Friend of a friend	1
Colleague	1
Step dad	1
Hairdresser	1
Professor	1
Significant other of a family member	1
A celebrity	1
Program participant	1

Table 4. Educational Exposure for Sample One

Have you heard of SLE?	Frequency	Percent	Valid Percent
Yes	245	72.9	72.9
No	91	27.1	27.1
Total	336		

Have you read about SLE?	Frequency	Percent	Valid Percent
Yes	65	19.3	19.4
No	270	80.4	80.6
Total	335		

Have you attended a lecture on SLE?	Frequency	Percent	Valid Percent
Yes	6	1.8	1.8
No	329	97.9	98.2
Total	336		

Have you learned about SLE in a class?	Frequency	Percent	Valid Percent
Yes	46	13.7	13.7
No	290	86.3	86.3
Total	336		

Table 5. Multiple Regression of Draft Items on Knowledge Scores

Item	B	Std. Error	Beta	t	Sign.
Item 20: Swollen and painful joints are symptoms of lupus.	-.051	.007	-.197	-7.678	.000
Item 28: Lupus can lead to difficulties with memory.	-.049	.008	-.146	-6.454	.000
Item 23: Scientists believe that hormones, genetics and the environment are all involved in causing lupus.	-.052	.007	-.176	-7.765	.000
Item 25: Patients are encouraged to minimize stressful life events.	-.037	.006	-.147	-6.015	.000
Item 9: African Americans are more likely to be diagnosed over other racial groups.	-.035	.008	-.094	-4.514	.000
Item 13: The degree of symptoms in people with lupus is very similar.	-.036	.009	-.096	-4.088	.000
Item 33: Certain medications can cause lupus symptoms.	-.039	.008	-.105	-4.705	.000
Item 7: Men are more likely to be diagnosed with lupus than women.	-.037	.009	-.086	-4.091	.000
Item 4: Women who have lupus and are pregnant are considered to have a "high risk" pregnancy.	-.021	.005	-.085	-4.146	.000
Item 10: Lupus is a predictable disease.	-.027	.010	-.062	-2.815	.005
Item 34: Lupus can be "caught" by sharing personal items with someone who is diagnosed	-.022	.009	-.053	-2.419	.016
Item 32: People are born with a genetic predisposition to getting lupus (more likely to have it because of their genetic background).	-.016	.007	-.051	-2.342	.020
Item 16: Being diagnosed with lupus places an individual at greater risk for additional medical diagnoses.	.002	.001	.039	2.296	.022

Table 6. Item Difficulty, Item Correlation, Readability of Draft Version

Item	Item Difficulty With All (N)	Item Difficulty w/o DKs (N)	Item-total Corr.	Flesch Reading Ease	Flesch-Kincaid Reading Level
Item 1: Fatigue	0.295 (336)	0.733 (135)	0.630	42.6	9.0
Item 2: Immune count test	0.027 (335)	0.145 (62)	0.333	74.8	5.8
Item 3: Heart disease	0.171 (332)	0.877 (65)	0.575	---	16.5
Item 4: High risk pregnancy	0.298 (336)	0.944 (106)	0.562	67.5	7.5
Item 5: Steroid medication	0.147 (334)	0.817 (60)	0.542	29.5	11.1
Item 6: Digestive issues	0.123 (334)	0.732 (56)	0.575	47.5	10.0
Item 7: Men diagnosed more	0.158 (336)	0.768 (69)	0.597	72.6	5.8
Item 8: Same virus	0.122 (335)	0.804 (51)	0.484	95.9	2.8
Item 9: AA disparity	0.137 (336)	0.596 (52)	0.472	32.5	11.7
Item 10: Predictable disease	0.217 (336)	0.859 (85)	0.701	32.5	9.9
Item 11: Single gene	0.081 (335)	0.614 (44)	0.515	69.7	6.0
Item 12: Skin rashes	0.230 (335)	0.917 (84)	0.680	73.8	4.4
Item 13: Symptom similarities	0.182 (336)	0.693 (88)	0.728	57.2	8.0
Item 14: Risk of more diagnoses	0.230 (335)	0.917 (84)	0.707	17.3	14.3
Item 15: Aging	0.089 (336)	0.476 (63)	0.554	34.5	9.1
Item 16: Multiple diagnoses	0.188 (335)	0.940 (67)	0.667	42.6	9.0
Item 17: Jaundice	0.051 (334)	0.283 (60)	0.379	64.9	6.9
Item 18: Great Imitator	0.200 (335)	0.944 (71)	0.731	37.4	11.2
Item 19: Symptoms begin soon	0.188 (335)	0.887 (71)	0.698	42.6	9.0
Item 20: Swollen/painful joints	0.265 (336)	0.927 (96)	0.755	71.8	5.2
Item 21: Negative impact on work	0.232 (336)	0.788 (99)	0.699	47.8	10.5
Item 22: Treatment can cure	0.266 (335)	0.937 (95)	0.731	75.8	3.6
Item 23: Hormone, gene, envt.	0.182 (336)	0.871 (70)	0.675	41.5	10.9
Item 24: Hair loss	0.199 (336)	0.763 (59)	0.501	90.9	2.3
Item 25: Minimize stressful events	0.300 (336)	0.971 (104)	0.737	40.0	9.6
Item 26: Specific cause know	0.149 (335)	0.820 (61)	0.718	49.5	9.0
Item 27: Distinguish b/w cells	0.209 (335)	0.921 (76)	0.755	44.9	10.7
Item 28: Memory difficulties	0.134 (336)	0.804 (56)	0.638	42.6	9.0
Item 29: Treatment stand/similar	0.141 (334)	0.758 (62)	0.675	64.9	6.9
Item 30: No exercising	0.104 (336)	0.761 (46)	0.530	17.9	13.9
Item 31: Kidney disease	0.054 (334)	0.419 (43)	0.440	61.3	7.1
Item 32: Genetic predisposition	0.158 (336)	0.855 (62)	0.562	42.7	12.2
Item 33: Meds cause symptoms	0.098 (336)	0.611 (54)	0.531	31.5	10.3
Item 34: “Catching” lupus	0.265 (336)	0.881 (101)	0.683	50.4	9.4
Item 35: Sensitivity to the sun	0.164 (335)	0.859 (64)	0.662	52.8	8.3
Item 36: Bipolar diagnosis	0.080 (336)	0.563 (48)	0.476	10.5	14.2
Item 37: Resolved skin rash	0.143 (335)	0.828 (58)	0.684	60.7	7.7
Item 38: Common for Caucasians	0.066 (335)	0.458 (48)	0.368	26.6	13.5
Overall			*0.960*	*49.3*	*8.9*

Table 7. Frequencies of LKQ-Draft Responses

	Item	Correct Response	Answered Correctly	Answered Incorrectly (w/o DKs)	Answered Don't Know
1	Fatigue is rarely experienced for lupus patients.	False	99(29.5%)	36 (10.7%)	201(59.8%)
2	The "immune count test" is the one used for diagnosing lupus.	False	9(2.7%)	53(15.8%)	273(81.3)
3	Lupus increases an individual's risk of premature cardiovascular disease (heart disease)	True	57(17.0%)	8(2.4%)	267 (79.5%)
4	Women who have lupus and are pregnant are considered to have a "high risk" pregnancy.	True	100 (29.8%)	6(1.8%)	230(68.5)
5	Steroid medication has the fewest negative side effects.	False	49(14.6%)	11(3.3%)	274(81.5%)
6	Patients with lupus experience more digestive issues, causing them to need to use the restrooms more often.	True	41(12.2%)	15(4.5%)	278(82.7%)
7	Men are more likely to be diagnosed with lupus than women.	False	53(15.8%)	16(4.8%)	267(79.5%)
8	Lupus us caused by the same virus that is linked to HIV.	False	41(12.2%)	10(3.0%)	284(84.5%)
9	African Americans are more likely to be diagnosed over other racial groups.	True	31(9.2%)	21(6.3%)	284(84.5%)
10	Lupus is a predictable disease.	False	73(21.7%)	12(3.6%)	251(74.7%)
11	Scientists believe there is a single gene that causes lupus.	False	27(8.0%)	17(5.1%)	291(86.6%)
12	Skin rashes are symptoms of lupus.	True	77(22.9%)	7(2.1%)	251(74.7%)
13	The degrees of symptoms in people with lupus are very similar.	False	61(18.2%)	27(8.0%)	248(73.8%)
14	Being diagnosed with lupus places an individual at greater risk for additional medical diagnoses.	True	77(22.9%)	7(2.1%)	251(74.7%)
15	Aging triggers lupus.	False	30(8.9%)	33(9.8%)	273(81.3%)
16	There are multiple types of lupus diagnoses.	True	63(18.8%)	4(1.2%)	267(79.5%)
17	Yellowing of the skin (jaundice) is a common symptom of lupus.	False	17(5.1%)	43(12.8%)	274(81.5%)
18	Lupus is often called "the great imitator" because lupus mimics other health conditions.	True	67(19.9%)	4(1.2%)	264(78.6%)
19	Lupus is diagnosed soon after symptoms begin.	False	63(18.8%)	8(2.4%)	264(78.6%)
20	Swollen and painful joints are symptoms of lupus.	True	89(26.5%)	7(2.1%)	240(71.4%)
21	A diagnosis of lupus does not have a negative impact on a person's ability to work.	False	78(23.2)	21(6.3%)	237(70.5%)
22	Treatment can cure lupus.	False	89(26.5%)	6(1.8%)	240(71.4%)
23	Scientists believe that hormones, genetics, and the environment are all involved in causing lupus.	True	61(18.2%)	9(2.7%)	266(79.2%)
24	Hair loss is a symptom of lupus.	True	45(13.4%)	14(4.2%)	277(82.4%)

25	Patients are encouraged to minimize stressful life events.	True	101(30.1%)	3(0.9%)	232(69.0%)
26	The specific cause of lupus has been identified by research scientist.	False	50(14.9%)	11(3.3%)	274(81.5%)
27	The immune system of someone with lupus cannot distinguish between healthy cells and harmful cells.	True	70(20.8%)	6(1.8%)	259(77.1%)
28	Lupus can lead to difficulties with memory.	True	45(13.4%)	11(3.3%)	280(83.3%)
29	Treatment plans for lupus have been standardized and are similar.	False	47(14.0%)	15(4.5%)	272(81.0%)
30	Patients are encouraged to not exercise following diagnosis to help control disease progression.	False	35(10.4%)	11(2.2%)	290(86.3%)
31	Kidney disease is one of the first indicators of lupus.	False	18(5.4%)	25(7.4%)	291(86.6%)
32	People are born with a genetic predisposition to getting lupus (more likely to have it because of their genetic background).	True	53(15.8%)	9(2.7%)	274(81.5%)
33	Certain medications can cause lupus symptoms.	True	33(9.8%)	21(6.3%)	282(83.9%)
34	Lupus can be “caught” by sharing personal items with someone who is diagnosed.	False	89(26.5%)	12(3.6%)	235(69.9%)
35	Sensitivity to the sun is a concern for lupus patients.	True	55(16.4%)	9(2.7%)	271(80.7%)
36	Bipolar disorder is the most common co-occurring mental health diagnosis.	False	27(8.0%)	21(6.3%)	288(85.7%)
37	Lupus skin rashes that occur can be resolved easily with skin lotion.	False	48(14.3%)	10(3.0%)	277(82.4%)
38	Lupus is more common for Caucasians than for individuals of Hispanic, Asian, and Native American descent.	False	22(6.5%)	26(7.7%)	287(85.4%)

Table 8. Frequency of Sample Two demographic variables

Variable		N	Valid Percentage
Gender			
	Female	144	77.8
	Male	41	22.2
Marital Status			
	Married	137	73.3
	Single, never married	32	17.1
	Divorced	16	8.6
Race/Ethnicity			
	White	154	83.2
	African American	10	5.4
	Asian	3	1.6
	Latino/a	8	4.3
	Mixed Race	7	3.8
	Middle Eastern	1	0.5
	Native American	2	1.1
Age			
	20-24	13	7.1
	25-29	37	21.0
	30-34	67	36.7
	35-39	41	22.4
	40-44	17	9.2
	45-49	5	2.6
	50-54	3	1.6
Years of Education			
	12 (HS graduate)	16	8.6
	13	25	13.4
	14 (Associate Degree)	23	12.4
	15	12	6.5
	16 (Bachelor Degree)	63	33.9
	17	4	2.2
	18(Master Degree)	24	12.9
	19	5	2.7
	20 (Doctorate/Professional Degree)	14	7.5

Table 9. Disease Proximity for Sample Two

Have you been diagnosed with lupus?	Frequency	Percent	Valid Percent
Yes	3	1.6	1.6
No	182	97.3	98.4
Total	186		

Do you have an immediate family member with lupus?	Frequency	Percent	Valid Percent
Yes	4	2.1	2.2
No	182	96.8	97.8
Total	186		

Do you have an extended family member with lupus?	Frequency	Percent	Valid Percent
Yes	18	9.6	9.7
No	168	89.4	90.3
Total	186		

Do you know anyone else with lupus?	Frequency	Percent	Valid Percent
Yes	48	25.5	25.8
No	138	73.4	74.2
Total	186		

Table 10. Description of "Yes"

Immediate Family	Frequency
Mother	2
Omitted	2
Extended Family	**Frequency**
Aunt	2
Cousin	6
Aunts and Cousins*	1
Great Aunt	1
Husband's Uncle	1
Husband's Cousin	1
Paternal Aunt	2
Paternal Great-Grandmother	1
Through Marriage	1
Step Father-in-law	1
Other	**Frequency**
Friend	24
Former (colleague/friend)	2
Childhood/high school Friend	2
Friends' grandparent	1
Acquaintance	4
Family friend	3
Co-worker/Colleague	2
Friend, coworker, underwent testing myself**	1
Child's former teacher	1
Neighbor	1
Job Patient	1

*Cannot infer further, remains as an answer of 1
** Cannot infer further, remains an answer of 1

Table 11. Educational Exposure for Sample Two

Have you heard of SLE?	Frequency	Percent	Valid Percent
Yes	179		72.9
No	9	27.1	27.1
Total	188		

Have you read about SLE?	Frequency	Percent	Valid Percent
Yes	84	44.7	44.7
No	104	55.3	55.3
Total	188		

Have you attended a lecture on SLE?	Frequency	Percent	Valid Percent
Yes	6	3.2	3.2
No	181	96.3	98.8
Total	187		

Have you learned about SLE in a class?	Frequency	Percent	Valid Percent
Yes	24	12.8	12.8
No	163	86.7	87.2
Total	187		

Table 12. Item Difficulty, Item Discrimination, Item Correlation, Readability of Revised Version

Item	Item Difficulty With All (N)	Item Discrim.	Item-total Corr.	Flesch Reading Ease	Flesch-Kincaid Reading Level
Item 1: Swollen/painful joints	0.643(188)	74.6	0.626	71.8	5.2
Item 2: Memory Difficulties	0.316(187)	62.7	0.476	42.6	9.0
Item 3: Horm, Envir, Gene	0.380(187)	70.6	0.589	46.6	9.7
Item 4: Minimize stress	0.586(186)	74.4	0.662	40.0	9.6
Item 5: AA disparity	0.342(187)	46.2	0.400	32.5	11.7
Item 6: Symptoms Similar	0.388(188)	62.7	0.560	57.2	8.0
Item 7:Distingusih Cells	0.583(187)	84.1	0.707	44.9	10.7
Item 8: Medications cause	0.255(188)	51.0	0.447	31.5	10.3
Item 9: Men diagnosed more	0.319(188)	70.6	0.563	72.6	5.8
Item 10: High risk pregnancy	0.473(188)	68.6	0.575	67.5	7.5
Item 11: Predictable	0.535(185)	75.9	0.622	32.5	9.9
Item 12: Spread by sharing	0.706(187)	52.2	0.609	50.4	9.4
Item 13: Genetic predisposition	0.404(188)	45.1	0.446	45.0	11.6
Item 14: Risk of more diagnoses	0.535(187)	85.1	0.743	17.3	12.0
Item 15: Premature heart disease	0.251(187)	54.9	0.477	**	12.0
Item 16: Fatigue	0.606(188)	58.9	0.605	42.6	9.0
Item 17: Severity is similar	0.489(188)	66.7	0.608	29.5	11.1
Item 18: Great Imitator	0.468(188)	78.4	0.658	37.4	11.2
Item 19: Hair loss/thinning	0.439(187)	84.2	0.616	82.3	3.7
Item 20: Validity Item	1.00 (188)	---	---	---	---
Item 21: Skin rash	0.428(187)	64.3	0.560	73.8	4.4
Item 22: Sensitivity to sun	0.441(188)	70.6	0.595	52.8	8.3
Item 23: Immune count test	0.048(188)	11.7	0.246	74.8	5.8
Item 24: Years to diagnose	0.484(188)	66.7	0.593	66.1	6.2
Item 25: Immune system weak	0.711(187)	66.6	0.710	66.1	6.2
Item 26: Diagnose soon	0.380(187)	58.7	0.557	42.6	9.0
Item 27: Bipolar most common	0.128(188)	29.4	0.361	17.9	12.0
Item 28: Caucasians more	0.188(186)	43.1	0.403	26.6	12.0
Item 29: Take years to diagnose	0.495(188)	74.5	0.671	66.1	6.2
Item 30: Aging triggers	0.085(188)	13.7	0.185	34.5	9.1
Item 31: Kidney disease	0.085(188)	18.7	0.272	61.3	7.1
Item 32: Jaundice symptom	0.107(187)	20.1	0.256	64.9	6.9
Item 33: Multiple diagnoses	0.351(188)	60.8	0.523	42.6	9.0
Item 34: Treatment can cure	0.510 (188)	70.6	0.593	75.8	3.6
Overall			*0.940*	*49.6*	*8.7*

--indicates the item was not analyzed
** item exceeded the score range

Table 13. Frequencies of LKQ-Revised Responses

	Item	Correct Response	Answered Correctly	Answered Incorrectly (w/o DKs)	Answered Don't Know
1	Swollen and painful joints are symptoms of lupus.	True	121(64.4%)	2(1.1%)	65(34.6%)
2	Lupus can lead to difficulties with memory.	True	59(31.6%)	12(6.4%)	116(62.0%)
3	The onset of lupus is triggered by hormones, genetics and the environment.	True	71(38.0%)	9(4.8%)	107 (56.2%)
4	Patients are encouraged to minimize stressful life events.	True	109(58.6%)	4(2.2%)	73(39.2%)
5	African Americans are more likely to be diagnosed over other racial groups.	True	64(34.2%)	15(8.0%)	108(57.8%)
6	The degree of symptoms in people with lupus is very similar.	False	73(38.8%)	29(15.4%)	86(45.7%)
7	The immune system, of someone with lupus, cannot distinguish between healthy cells and harmful cells.	True	109(58.3%)	2(1.1%)	76(40.6%)
8	Certain medications can cause lupus symptoms.	True	48(25.5%)	19(10.1%)	121(64.4%)
9	Men are more likely to be diagnosed with lupus than women.	False	60(31.9%)	9(4.8%)	119(63.3%)
10	Women who have lupus and are pregnant are considered to have a high risk pregnancy.	True	89(47.3%)	6(3.2%)	93(49.5%)
11	Lupus is a predictable disease.	False	99(53.5%)	9(4.9%)	77(41.6%)
12	Lupus can be spread by sharing personal items with someone who is diagnosed.	False	132(70.6%)	9(4.8%)	46(24.6%)
13	People are born with a genetic predisposition for lupus (more likely to have it because of their genetic background).	True	76(40.4%)	8(4.3%)	104(55.3%)
14	Being diagnosed with lupus places an individual at greater risk for additional medical diagnoses.	True	100(53.5%)	1(0.5%)	86(46.0%)
15	Lupus increases an individuals' risk of premature cardiovascular disease (heart disease).	True	47(25.1%)	6(3.2%)	134(71.7%)
16	Fatigue is rarely experienced for lupus patients.	False	114(60.6%)	25(13.3%)	49(26.1%)
17	The severity of symptoms is similar across patients.	False	92(48.9%)	20(10.6%)	76(40.4%)
18	Lupus is often called *the great imitator* because lupus mimics other health conditions.	True	88(46.8%)	4(2.1%)	96(51.1%)
19	Hair loss/thinning is a symptom of lupus.	True	82(43.9%)	6(3.2%)	99(52.9%)
20	Please answer true for this item.	True	188(100%)	---	---
21	Skin rashes are symptoms of lupus.	True	80(42.8%)	5(2.7%)	102(54.5%)
22	Sensitivity to the sun is a concern for lupus patients.	True	83(44.1%)	5(2.7%)	100(53.2%)
23	The *immune count test* is the one test used for diagnosing lupus.	False	9(4.8%)	45(23.9%)	134(71.3%)
24	It may take many years to confirm a diagnosis.	True	91(48.4%)	7(3.7%)	90(47.9%)

25	The immune system of patients with lupus is weakened.	True	133(71.1%)	5(2.7%)	49(26.2%)
26	Lupus is diagnosed soon after symptoms begin.	False	71(38.0%)	18(9.6%)	98(52.4%)
27	Bi-polar disorder is the most common co-occurring mental health diagnosis for lupus patients.	False	24(12.8%)	19(10.1%)	145(77.1%)
28	Lupus is more common for Caucasians than for individuals of Hispanic, Asian, and Native American decent.	False	35(18.8%)	20(10.8%)	131(70.4%)
29	It may take many years to confirm a diagnosis.	True	93(49.5%)	5(2.7%)	90(47.9%)
30	Aging triggers lupus.	False	16(8.5%)	23(12.2%)	149(79.3%)
31	Kidney disease is one of the first indicators of lupus.	False	16(8.5%)	23(12.2%)	149(79.3%)
32	Yellowing of the skin (jaundice) is a common symptom of lupus.	False	20(10.7%)	30(16.0%)	137(73.3%)
33	There are multiple types of lupus diagnoses.	True	66(35.1%)	11(5.9%)	111(59.0%)
34	Treatment can cure lupus.	False	96(51.1%)	7(3.7%)	85(45.2%)

APPENDIX A:

Medical provider Interview Protocol

A. Introduction
    1. Thanks for coming- brief explanation of the protocol. This should take no longer than 60 minutes. Describe importance of information they are providing-You are part of a critical phase of developing the first ever lupus knowledge questionnaire to assess both patients' disease knowledge and knowledge of SLE among the general public.
    2. Explain and read (provide) Informed Consent and then they will be asked to complete a demographic survey on my laptop through Qualtrics.

B. Purpose
    1. I want the questionnaire to be physician and patient driven which is why I want to hear about your experiences with living with lupus.
    2. I want to know about your ideas, suggestions and comments about what questions and content should be included in an SLE knowledge questionnaire. As you are a medical professional who has had experience providing patients with information related to lupus you know what questions are asked or what should be asked. I want to use that and your medical background to understand how I can create a useful questionnaire.

C. Procedure
    1. Session will be recorded- This is all confidential, your name will not be collected with your responses. Anything you say here is only used for the purpose of my research and the LKQ.

Begin – turn on recorder

For the first set of questions, I'm going to ask you about your experiences with patients and your thoughts on the type of knowledge they want to gain, the type of knowledge you think they should have, and any misconceptions they have about SLE. For the second set of questions, I'm going to ask you about the resources you provide to patients. And finally, for the third set of questions, I'm going to ask you about knowledge you think would be useful for family members or those caring for people with SLE to have, as well as people within the general public.

1. Tell me a little bit about your medical background and the types of conditions you see in patients?

SET 1: <u>Thoughts on the type of knowledge you think patients should have</u>

2. What information do you think is important for patients to know?
    a) What are some specific questions related to the **cause** of SLE that would be beneficial to assess in a knowledge questionnaire? (E.g. SLE is caused by smoking – T/F)
    b) What are some specific questions related to the **symptoms** that occur in SLE that would be beneficial to assess? (E.g. Groups of symptoms of SLE are often times described as flares- T/F)

c) What are some specific questions related to the **course** of SLE that would be beneficial to assess? (E.g. The average length of time it takes to receive a diagnosis is 5 years –T/F)
d) What are some specific questions related to the **controllability** of SLE that would be beneficial to assess? (E.g. Medication use? Exercise? Eating habits?)
e) What are some specific questions related to the **chronic style** of SLE that would be beneficial to assess? (E.g. Longevity? Quality of life?)

3. What misconceptions do patients tend to have about their diagnosis?
4. What questions regarding SLE do patients not ask about that they should?

SET 2: <u>The resources used to educate patients</u>

1. How do you educate patients about SLE?
    a) **Prompt:** Could you explain what you say to someone who is diagnosed and walk me through your explanation of the disease?
2. What resources do you provide them?
    a) **Prompt**: Pamphlets, handouts (from where) or reliable internet sources (from where)
        1. What has been your experience with this?
        2. How well does this or does this not work?
3. What resources do you have at your disposal to assist you in providing education/knowledge to your SLE patients? (If not already answered from the above question)
4. What other resources (if any) would be helpful to have at your disposal when trying to educate patients?
5. Are there any resources that you find counter-productive? For instance, are there are websites that give patients an unrealistic view of the disease?

SET 3: <u>Useful for family members/caregivers/general public to have</u>

1. What should people know about SLE to have a good general understanding of the illness and how it is experienced by people? (i.e. causes, symptoms, treatment, etc.) (Not patients)
2. What information do you think is important for family members or caretakers of patients to know?
3. What misconceptions do you think the general public tends to have about the diagnosis?
4. Any other thoughts, comments or suggestions before we conclude the interview.

THANK YOU! After I compile all of the information from these interviews I will create a draft of the LKQ. Once the draft has been created I would like to contact you and get some feedback on the questions before I begin testing it within patient and community samples. Would you be okay with this?

APPENDIX B:
Materials for Medical Provider Verification

Here you will be asked to read over the lupus knowledge questionnaire draft and provide a relevance score for each item (*1= not relevant/exclude to 4= highly relevant/keep as is)*. After providing a 1-4 score for each item then you will be asked to provide feedback on clarity and accuracy. This will give you the opportunity to provide edits or comments related to that item.

Relevance: Is the item relevant to be involved in a general SLE-specific disease knowledge?

Clarity: Is the item clear in regard to the wording?

Accuracy: Does the item contain accurate medical information?

If you indicate a 2 or a 3 please provide recommendations or alterations that could be added to make the question be rated a 4.

*****

This questionnaire will be given to a community sample of individuals for initial testing. Therefore, it is meant to be a more generalist questionnaire rather than specific details for patients or providers.

	Item on the lupus knowledge questionnaire (LKQ)	Relevance
1	Hair loss is a symptom of lupus –ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
2	Skin rashes are symptoms of lupus–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
3	Sensitivity to the sun is a concern for lupus patients–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
4	Swollen and painful joints are symptoms of lupus–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
5	Yellowing of the skin (jaundice) is a common symptom of lupus–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
6	Kidney disease is one of the first indicators of lupus–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
7	The degree of symptoms in people with lupus are very similar–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
8	Fatigue is rarely experienced for lupus patients–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		

9	Lupus is often called “the great imitator” because lupus mimics other health conditions–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
10	Lupus is diagnosed soon after symptoms begin–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
11	The “immune count test” is the one test used for diagnosing lupus–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
12	The immune system, of someone with lupus, cannot distinguish between healthy cells and harmful cells–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
13	Men are more likely to be diagnosed with lupus than women–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
14	Lupus is caused by the same virus that is linked to HIV–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
15	Scientists believe there is a single gene that causes lupus–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
16	African Americans are more likely to be diagnosed over other racial groups–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		

17	The specific cause of lupus has been identified by research scientists–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
18	People are born with a genetic predisposition to getting lupus (more likely to have it because of their genetic background) – ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
19	Scientists believe that hormones, genetics, and the environment are all involved in causing lupus–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
20	Aging triggers lupus–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
21	There are multiple types of lupus diagnoses–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
22	Certain medications can cause lupus symptoms –ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
23	Lupus can be "caught" by sharing personal items with someone who is diagnosed–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
24	Lupus is more common for Caucasians than for individuals of Hispanic, Asian, and Native American decent–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		

25	Treatment can cure lupus–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
26	Treatment plans for lupus have been standardized and are all similar–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
27	Steroid medication has the fewest negative side effects–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
28	Lupus is a predictable disease–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
29	Patients are encouraged to not exercise following diagnosis to help control disease progression–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
30	Being diagnosed with lupus places an individual at greater risk for additional medical diagnoses–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
31	Patients are encouraged to minimize stressful life events–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
32	Bi-polar disorder is the most common co-occurring mental health diagnosis–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		

33	Women who have lupus and are pregnant are considered to have a “high risk” pregnancy–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
34	Lupus skin rashes that occur can be resolved easily with skin lotion–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
35	Lupus can lead to difficulties with memory–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
36	Patients with lupus experience more digestive issues, causing them to need restrooms more often–ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
37	A diagnosis of lupus does not have a negative impact on a person’s ability to work–ANS: F	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		
38	Lupus increases an individual’s risk of premature cardiovascular disease (heart disease) –ANS: T	
Do you have any changes that you would like to see applied in terms of accuracy or clarification of the item? Add any comments or edits below.		

APPENDIX C:

Demographic and Educational Exposure/ Disease Proximity Questions

Instructions: Fill out all demographic items below as honestly as possible. Please fill in boxes or type responses when necessary. Please read all of the directions before continuing though the survey.

1) What gender do you identify with?
   - Female
   - Male
   - Other (please specify) _____

2) With which race and/or ethnicity do you identify (select all that apply)
   - Asian
   - Pacific Islander
   - Black/African American
   - Hispanic/Latino/a
   - Native American
   - White/Caucasian
   - Mixed

3) What is your current age? _____

4) Are you currently a student?
   - Yes, high school
   - Yes, part-time college
   - Yes, full-time college
   - No

5) What is your marital status?
   - Single (never married)
   - Married
   - Separated
   - Divorced

6) How many years of education do you have? _____

(Educational exposure Items)

	Yes	No
1. Have you heard of SLE?	❍	❍
2. Have you read about SLE?	❍	❍
3. Have you attended a lecture about SLE?	❍	❍
4. Have you learned able SLE in a class?	❍	❍

How confident are you in the accuracy of your current knowledge about SLE?

	Not Confident	Somewhat Confident	N/A or Unsure Confidence	Confident	Extremely Confident
Lupus	❍	❍	❍	❍	❍

(*Disease Proximity Items*)

You may choose to leave these items blank if you are not comfortable disclosing. Please consider responding if you are comfortable. Your responses are confidential.

a) Have you been diagnosed with Lupus? ____ Yes _____No
b) Do you have an immediate family member diagnosed with Lupus? ___Yes ___ No
c) Has anyone in your extended family ever been diagnosed with Lupus? __Yes ___No
d) Do you know anyone else who has been diagnosed with Lupus? ___ Yes ____ No

**** LKQ will appear here****

Following completion of the questionnaire participants will be asked to complete these final two items.

How well do you believe you did on the task above? (0= I did not get any items correct, 100= I got all the items correct.)

0%_____100%

Based on your knowledge of lupus how do you believe you compare to the average person?

❍ I have more knowledge than the average person
❍ I have some more knowledge than the average person
❍ I am the same as the average person
❍ I have less knowledge than the average person
❍ I know nothing compared to the average person

APPENDIX D:

CVI Verification Feedback from Providers

	Original	P1 score	P1 edits	P2 score	P2 edits	P3 score	P3 edits	Agree Rate
1 *a*	Hair loss is a symptom of lupus	4	hair loss or thinning hair	4		3		100%
2 *a*	Skin rashes are symptoms of lupus	4	Butterfly rash across bridge of nose and cheeks.	4		3		100%
3 *a*	Sensitivity to the sun is a concern for lupus patients	3		4		4		100%
4 *ab*	Swollen and painful joints are symptoms of lupus	4	Patients usually complain of joint stiffness and pain that does not resolve after activity.	4		2		67%
5 *c*	Yellowing of the skin (jaundice) is a common symptom of lupus	1		4	Generally not true unless has hepatitis with the disease false	1		33%
6 *a*	Kidney disease is one of the first indicators of lupus	1		4	I cannot agree- false	3		67%
7 *ab*	The degree of symptoms in people with lupus are very similar	2 /4**	People are individually affected by this disease in different ways. Some people have more severe symptoms while others have less severe symptoms.	4	not true- false	1		67%
8 *a*	Fatigue is rarely experienced for lupus patients	4	One of the first complaints of patient presenting with lupus signs is generalized fatigue.	4	false	4		100%
9 *a*	Lupus is often called “the great imitator” because lupus mimics other	4		3		3		100%

	health conditions							
10 *a*	Lupus is diagnosed soon after symptoms begin	1/4 **	It may take many years for the affirmative of the diagnosis.	4	false	1		67%
11 *a*	The "immune count test" is the one test used for diagnosing lupus	1		4	false	3		67%
12 *a*	The immune system, of someone with lupus, cannot distinguish between healthy cells and harmful cells	4	Patients with lupus usually have a weakened immune system than others.	4	not true- it is the autoantibodies	2		67%
13 *b*	Men are more likely to be diagnosed with lupus than women	1		4		1		33%
14 *d*	Lupus is caused by the same virus that is linked to HIV	1		2		1		0%
15 *d*	Scientists believe there is a single gene that causes lupus	1		2		1		0%
16 *ab*	African Americans are more likely to be diagnosed over other racial groups	4		4	I would have thought otherwise- Incidence maybe higher- but due to economic factors and access to decent care- they are less likely to be diagnosed earlier.	3		100%
17 *d*	The specific cause of lupus has been identified by research scientists	1		4		1		33%

18 *ab*	People are born with a genetic predisposition to getting lupus (more likely to have it because of their genetic background)	4		4		2		67%
19 *ab*	Scientists believe that hormones, genetics, and the environment are all involved in causing lupus	3		3	Hormones? Environment? -causing?- modulating maybe not cause	3		100%
20 *c*	Aging triggers lupus	1		3		1		33%
21 *ab*	There are multiple types of lupus diagnoses	4		4		2		67%
22 *ab*	Certain medications can cause lupus symptoms	4		4		3		100%
23 *b*	Lupus can be "caught" by sharing personal items with someone who is diagnosed	1		4		1		33%
24 *c*	Lupus is more common for Caucasians than for individuals of Hispanic, Asian, and Native American decent	2		4		1		33%
25 *a*	Treatment can cure lupus	1/4 **	This cannot be treated, but symptoms may be managed.	4		2		67%
26 *d*	Treatment plans for lupus have been standardized and are all similar	1/4 **	All patients have different manifestations of lupus, therefore treatment would be different.	4		1		67%
27 *d*	Steroid medication has	2		4		1		33%

	the fewest negative side effects							
28 *b*	Lupus is a predictable disease	1		4		1		33%
29 *d*	Patients are encouraged to not exercise following diagnosis to help control disease progression	1/4 **	All patients have different manifestations of lupus, therefore treatment would be different.	4		1		67%
30 *a*	Being diagnosed with lupus places an individual at greater risk for additional medical diagnoses	4	Lupus may affect multiple organs, which then may causes other diseases.	4		1		67%
31 *b*	Patients are encouraged to minimize stressful life events	4	stress may decrease immune system, and also flare symptoms	4		3		100%
32 *c*	Bi-polar disorder is the most common co-occurring mental health diagnosis	1		4		1		33%
33 *ab*	Women who have lupus and are pregnant are considered to have a “high risk” pregnancy	4		4		3		67%
34 *d*	Lupus skin rashes that occur can be resolved easily with skin lotion	1		4		1		33%
35 *ab*	Lupus can lead to difficulties with memory	4		4		3		67%
36 *d*	Patients with lupus experience more digestive issues, causing them to need restrooms more often	4		3		2		67%

37 *d*	A diagnosis of lupus does not have a negative impact on a person's ability to work	1/4 **	this is a life changing diagnosis	4		3		100%
38 *a*	Lupus increases an individual's risk of premature cardiovascular disease (heart disease)	4		4		4		100%

a = items retained for the revised version based on CVI
b = items retained for the revised version based on regression
c = items retained for the revised version based on item difficulty/subjective
d = items excluded from revised version
(Of note, the items may or may not have gone through wording edits based off feedback between the draft version and the revised version)
** = indicates items as their original score/score change after edits were accounted for

APPENDIX E:

LKQ Items in CSM Dimensions

Identity	**P1**	**P2**	**P3**	**CVI**
Jaundice is a common symptom	1	4	1	33%
Kidney disease is the first disease indicator	1	4	3	67%
Swollen/painful joint are common symptoms	4	4	2	67%
Skin rashes are symptoms	4	4	3	100%
Sun sensitivity is a concern	3	4	4	100%
Hair loss is a symptom	4	4	3	100%
Fatigue is not experienced	4	4	4	100%

Cause	**P1**	**P2**	**P3**	**CVI**
Single gene causes lupus	1	2	1	0%
Aging triggers lupus	1	3	1	33%
Specific cause is known	1	4	1	33%
Men diagnosed more	1	4	1	33%
Same virus as HIV	1	4	1	33%
Caucasian are diagnosed more than other ethnicities.	2	4	1	33%
Immune system cannot distinguish cells	4	4	2	67%
Genetic predisposition for lupus	4	4	2	67%
African Americans more often diagnosed	4	4	3	100%
Medications cause symptoms	4	4	3	100%
Hormone, genes, environment all play a role	3	3	3	100%

Time-line	**P1**	**P2**	**P3**	**CVI**
Can be caught by sharing items.	1	4	1	33%
Lupus is diagnosed soon	1- Edits	4	3	67% / 100%
“Immune count test” is the one test used.	1	4	3	67%

Controllability/Curability	**P1**	**P2**	**P3**	**CVI**
Lupus is a predictable disease	1	4	1	33%
Patients are encouraged to not exercise	1	4	1	33%
Steroid medications cause least side effects.	2	4	1	33%
Treatment can cure lupus.	1- Edits	4	2	33% / 67%
Treatments are standard/similar.	1- Edits	4	1	33% / 67%
Symptom Severity is the same for patients	2- Edits	4	1	33% / 67%
Additional diagnoses are common after lupus.	4	4	1	67%
Patients are encouraged to minimize stress.	4	4	3	100%

Consequence	**P1**	**P2**	**P3**	**CVI**
Bi-polar is the most common co-morbid mental health.	1	4	1	33%
Skin lotion can eliminate rash symptoms	1	4	1	33%
There are multiple types of lupus diagnoses.	4	4	2	67%
Digestive issues are increased	4	3	2	67%
Patients have negative work abilities	1- Edits	4	3	67% / 100%
Lupus is also known as the Great Imitator.	4	3	3	100%
Patients have memory concerns	4	4	3	100%
Mothers with lupus will have a high risk pregnancy	4	4	3	100%
Premature heart disease is a risk	4	4	4	100%

APPENDIX F:

Draft LKQ Version

Instructions: Please complete the following questionnaire that contains 38 items that will ask you about your general knowledge about systemic lupus erythematosus, more commonly referred to as *lupus*. The items are all designed as True/False or Don't Know. Please answer the following items based on your current level of knowledge about lupus and be as honest as you can.

	Item	True	False	DK
1	Fatigue is rarely experienced for lupus patients		False	
2	The "immune count test" is the one test used for diagnosing lupus		False	
3	Lupus increases an individual's risk of premature cardiovascular disease (heart disease)	True		
4	Women who have lupus and are pregnant are considered to have a "high risk" pregnancy	True		
5	Steroid medication has the fewest negative side effects		False	
6	Patients with lupus experience more digestive issues, causing them to need to use restrooms more	True		
7	Men are more likely to be diagnosed with lupus than women		False	
8	Lupus is caused by the same virus that is linked to HIV		False	
9	African Americans are more likely to be diagnosed over other racial groups	True		
10	Lupus is a predictable disease		False	
11	Scientists believe there is a single gene that causes lupus		False	
12	Skin rashes are symptoms of lupus	True		
13	The degree of symptoms in people with lupus are very similar		False	
14	Being diagnosed with lupus places an individual at greater risk for additional medical diagnoses	True		
15	Aging triggers lupus		False	
16	There are multiple types of lupus diagnoses	True		
17	Yellowing of the skin (jaundice) is a common symptom of lupus		False	
18	Lupus is often called "the great imitator" because lupus mimics other health conditions	True		
19	Lupus is diagnosed soon after symptoms begin		False	
20	Swollen and painful joints are symptoms of lupus	True		
21	A diagnosis of lupus does not have a negative impact on a person's ability to work		False	
22	Treatment can cure lupus		False	
23	Scientists believe that hormones, genetics, and the environment are all involved in causing lupus	True		
24	Hair loss is a symptom of lupus	True		
25	Patients are encouraged to minimize stressful life events	True		
26	The specific cause of lupus has been identified by research scientists		False	
27	The immune system, of someone with lupus, cannot distinguish between healthy cells and harmful cells	True		
28	Lupus can lead to difficulties with memory	True		
29	Treatment plans for lupus have been standardized and are similar		False	
30	Patients are encouraged to not exercise following diagnosis to help control disease progression		False	
31	Kidney disease is one of the first indicators of lupus		False	
32	People are born with a genetic predisposition to getting lupus (more likely to have it because of their genetic background)	True		
33	Certain medications can cause lupus symptoms	True		

34	Lupus can be “caught” by sharing personal items with someone who is diagnosed		False	
35	Sensitivity to the sun is a concern for lupus patients	True		
36	Bi-polar disorder is the most common co-occurring mental health diagnosis		False	
37	Lupus skin rashes that occur can be resolved easily with skin lotion		False	
38	Lupus is more common for Caucasians than for individuals of Hispanic, Asian, and Native American decent		False	

APPENDIX G:

Revised LKQ Version

Instructions: Please complete the following questionnaire that contains 34 items that will ask you about your general knowledge about systemic lupus erythematosus, more commonly referred to as *lupus*. The items are all designed as True/False or Don't Know. Please answer the following items based on your current level of knowledge about lupus and be as honest as you can.

	Item	True	False	DK
1	Swollen and painful joints are symptoms of lupus.	True		
2	Lupus can lead to difficulties with memory.	True		
3	The onset of lupus is triggered by hormones, genetics and the environment.	True		
4	Patients are encouraged to minimize stressful life events.	True		
5	African Americans are more likely to be diagnosed over other racial groups.	True		
6	The degree of symptoms in people with lupus is very similar.		False	
7	The immune system, of someone with lupus, cannot distinguish between healthy cells and harmful cells.	True		
8	Certain medications can cause lupus symptoms.	True		
9	Men are more likely to be diagnosed with lupus than women.		False	
10	Women who have lupus and are pregnant are considered to have a high risk pregnancy.	True		
11	Lupus is a predictable disease.		False	
12	Lupus can be spread by sharing personal items with someone who is diagnosed.		False	
13	People are born with a genetic predisposition for lupus (more likely to have it because of their genetic background).	True		
14	Being diagnosed with lupus places an individual at greater risk for additional medical diagnoses.	True		
15	Lupus increases an individuals' risk of premature cardiovascular disease (heart disease).	True		
16	Fatigue is rarely experienced for lupus patients.		False	
17	The severity of symptoms is similar across patients.		False	
18	Lupus is often called *the great imitator* because lupus mimics other health conditions.	True		
19	Hair loss/thinning is a symptom of lupus.	True		
20	Please answer true for this item.	True		
21	Skin rashes are symptoms of lupus.	True		
22	Sensitivity to the sun is a concern for lupus patients.	True		
23	The *immune count test* is the one test used for diagnosing lupus.		False	
24	It may take many years to confirm a diagnosis.	True		
25	The immune system of patients with lupus is weakened.	True		
26	Lupus is diagnosed soon after symptoms begin.		False	
27	Bi-polar disorder is the most common co-occurring mental health diagnosis for lupus patients.		False	
28	Lupus is more common for Caucasians than for individuals of Hispanic, Asian, and Native American decent.		False	
29	It may take many years to confirm a diagnosis.	True		
30	Aging triggers lupus.		False	
31	Kidney disease is one of the first indicators of lupus.		False	
32	Yellowing of the skin (jaundice) is a common symptom of lupus.		False	
33	There are multiple types of lupus diagnoses.	True		
34	Treatment can cure lupus.		False	

Figure 1: LKQ- draft Total Percentage (out of 100%, 38 items)

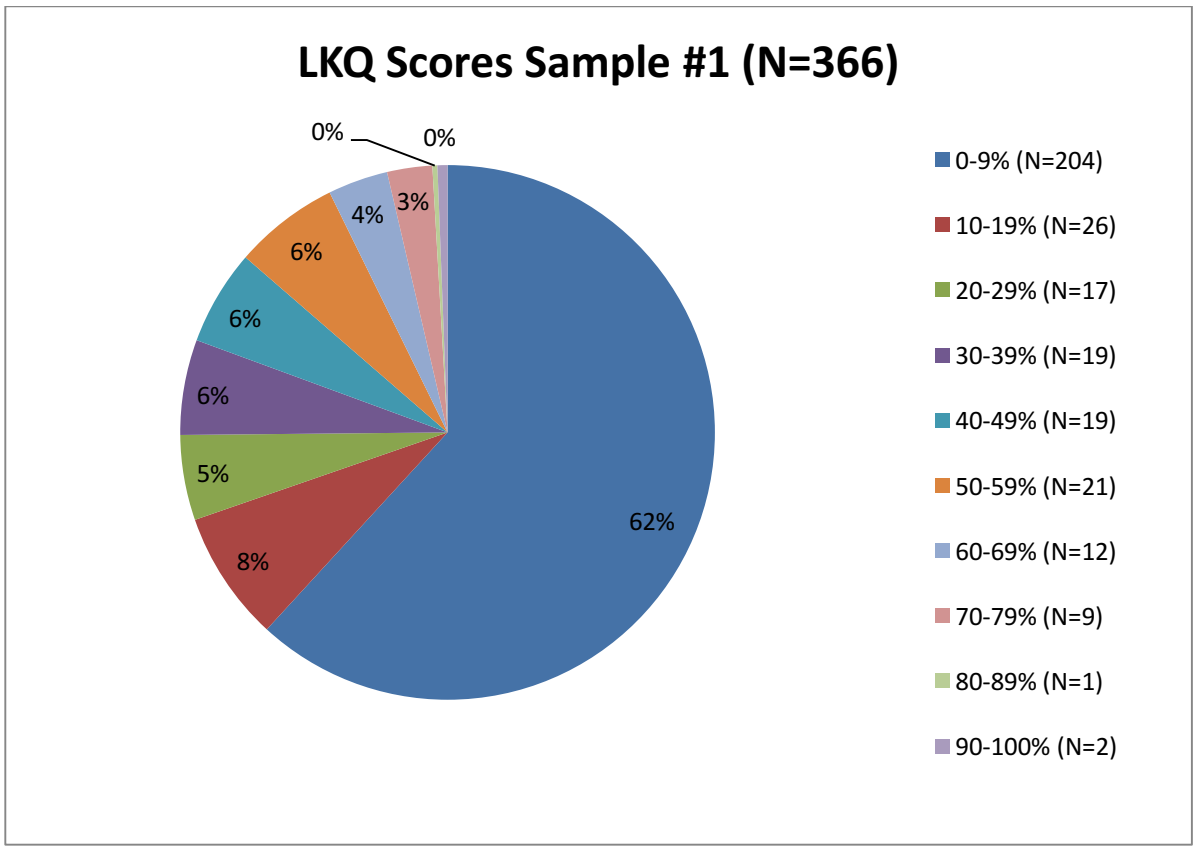

Figure 2: LKQ- revised Total Percentage (out of 100%, 34 items)