The Perceived Effectiveness of School-Based Accommodations for Students with Systemic Lupus Erythematosus

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The Perceived Effectiveness of School-Based Accommodations for Students with Systemic Lupus Erythematosus

A Dissertation by

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Submitted in partial fulfillment of the requirements for the degree of

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The Perceived Effectiveness of School-Based Accommodations for Students with Systemic Lupus Erythematosus

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Your deaths from lupus were not in vain:  
Sophia, Jasmine, and Mom.

Thank you to my parents who did not abandon their 1-year old baby girl during their narrow escape from the Cambodian genocide. The sacrifices my refugee parents made for me are countless and will never be forgotten. Their consistent example of hard work, personal integrity, and commitment to family and faith were the ingredients which turned a baby refugee into a PhD.

I would like to thank my friends who have faithfully prayed for me and encouraged me during my educational journey. Thank you for faithfully standing by me, especially after the death of my mother. Ninety-eight year old Velma Harrell deserves special recognition for crossing generational and racial lines by becoming my beloved mentor for almost 30 years.

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Thank you to each reader who has an interest in reading this dissertation. May this inspire more intersectional studies involving medicine and education. May you always enjoy good health and/or complete remission.
ABSTRACT

The Perceived Effectiveness of School-Based Accommodations for Students with Systemic Lupus Erythematosus

by MaryAnn Seng

Pediatric patients with systemic lupus erythematosus battle a chronic, autoimmune illness which can be life-threatening in cases of vital organ involvement. Disease activity and severity is harsher during the developmental period of childhood and adolescence than during adulthood. Lupus symptoms and medication side effects may cause patients to experience neurocognitive and/or physical impairment. The cyclical nature of the illness consists of flare and remission phases. The present study explored the topic of pediatric lupus in the school setting due to the severe impact of the illness on youth. It examined the accommodations provided to students, as well as the patients’ preferred accommodations. Anonymous English and Spanish surveys were placed in the waiting rooms of three lupus clinics in three different California counties. The target population consisted of middle and high school students who have the diagnosis of lupus. Surveys were completed by the students or by their parents/guardians. They were asked to list the ideal educational accommodations that is needed to earn a high school diploma. They were also asked about their present accommodations and services. A total of 39 surveys were collected in approximately five months. Based on the grade point averages, all of the students in the sample were passing their classes. The educational accommodation that was preferred most often by the pediatric patients with lupus was the need for extended time to complete assignments. It was the top choice among the presently given-accommodations list and the ideal accommodations list.
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Chapter One: Introduction

The "Americans with Disability Act" and section 504 of the "American Rehabilitation Act of 1973" are federal laws that have allowed the implementation of "reasonable accommodations" within the workplace, as well as through 504 plans in the school environment. Such laws have allowed individuals with disabilities to integrate into their communities and participate in tasks and activities that are comparable to their typically developing peers. Although the word "accommodation" is a commonly used term, the “Individuals with Disabilities Education Act” (IDEA) does not carefully define that exact term in the law. The present study will employ Harrison’s definition, since it is the result of a comprehensive literature review: "Changes in practices that hold a student to the same standard as students without disabilities (i.e. grade-level academic content standard) but provide a differential boost (i.e. more benefit to those with a disability than those without) to mediate the impact of the disability on access to the general education curriculum (i.e. level the playing field)” (Harrison, 2013, p. 556).

Students with medical needs are entitled to accommodations in the classroom, but data are lacking as to how many pediatric patients with systemic lupus erythematosus (abbreviated to "lupus") are actually provided with that support. Old data from a study by Lahita (1988) showed that 12.5% of lupus patients were diagnosed with some type of learning disorder, such as dyslexia. Certain medical conditions, like lupus, may not present itself as impaired as other conditions, which may result in patients being overlooked by educators. Families may not know their rights, so students are left without any academic support.

The topic of systemic lupus erythematosus (SLE) and the educational environment is important due to the findings of one study which links the two topics involving adult patients
with autoimmune conditions. This study sought to examine any association between mortality from autoimmune illnesses and school teaching. Walsh and DeChello (2001) calculated the proportional mortality ratios from the death certificates of teachers during the years of 1985-1995. The results showed excess mortality among elementary and secondary school teachers from autoimmune illnesses. If the health of teachers with lupus is at risk in the school setting, pediatric patients who are exposed to the same environmental setting likely are at equal, or possibly even more, risk with their immunosuppressed conditions. Polychlorinated biphenyls (PCB's) remain in many classrooms across America even though such chemicals were banned four decades ago (Webber & Irvine, 2019). Older schools are at more risk of having the illegal substances in their "caulk, ceiling tiles, and paint". Webber and Irvine (2019) stated that the levels of the banned chemicals have been shown to contain much higher levels than what is allowed by the Environment Protection Agency (EPA).

A Harvard health professor, Dr. Robert Herrick, studied the specific use of PCB’s in school buildings and reported that PCB's were commonly used as a plasticizer in the caulk which were used in school buildings built before 1980. The EPA later learned that such materials can be inhaled or ingested via dust or air. Because of that, other surfaces can absorb the chemicals, which would result in the continual existence of the PCB’s. Researchers have established that PCB’s are highly dangerous to those with lupus (Mak & Tay, 2014, Tsai et al., 2007).

It is that medical risk in the school environment that inspired this researcher to examine the best educational accommodations for secondary students with systemic lupus erythematosus. By understanding what types of support pediatric patients currently have and knowing the supports that they would like to have, steps can be taken to bridge any disparities for the sake of patients’ medical, psychological, and educational functioning.
Statement of the Problem

Systemic Lupus Erythematosus is one of the most overlooked diseases as it slowly robs pediatric patients of their lives and/or their quality of life. Lupus is usually most severe during the adolescent years, so extra precaution must be taken during that developmental period in order to preserve patients' vital organs. Despite the young patients’ use of powerful immunosuppressants, school attendance remains a legal mandate. Receiving services through programs such as the "Home and Hospital Instruction Program" (CA Ed Code 48206.3) is a possibility for a small percentage of severe cases, but the majority of chronically ill pediatric patients must continue to attend school on a daily basis.

School can then become a possible risk factor due to the exposure of various bacteria and viruses in the educational environment. The stress that is often associated with school can also increase the psychological risk, especially to chronically ill patients who struggle to keep up with academic demands. That stress can make patients more susceptible to increased disease activity due to the psychoneuroimmunological connection. The problem to be addressed in this study encompasses possible ways to protect pediatric patients with lupus from increased harm to their health status.

Purpose Statement

The purpose of the present study was to examine the present and preferred accommodations for students with systemic lupus erythematosus. The findings from this study may allow physicians and educators to make research-based recommendations for the benefit of pediatric patients' functioning in the school environment. The recommendations can then be implemented in students’ 504 Plans and Individualized Education Plans (IEP’s). The present
study seeks to discover which educational accommodations are perceived by adolescents to be most beneficial for their academic achievement and physical well-being at school.

This exploratory effort will contribute to the present literature by adding to our understanding of the educational needs of SLE from the viewpoints of pediatric patients themselves. In general, pediatric quality-of-life issues among those with systemic lupus erythematosus have not been examined as closely as quality-of-life issues in adults. Now that physicians and scientists have produced research-driven evidence on the severity and morbidity of pediatric lupus, it is crucial to seek ways to ease the condition beyond medical treatment alone.

**Research Questions**

Research Question 1a: What are the educational accommodations that participants are presently receiving? The participants were asked to rank their current accommodations (which have already been provided by their schools) according to their helpfulness toward earning a high school diploma.

Research Question 1b: What are the participants’ favorite accommodations in rank order out of the presently-received accommodations? The participants were asked to rank their current accommodations (which have already been provided by their schools) according to their helpfulness toward earning a high school diploma.

Research Question 2: What are the participants’ preferred or ideal accommodations in rank order in terms of helpfulness toward earning a high school diploma?

Research Question 3: Is there any relationship between participants' grade point average and their total number of medications?
Research Question 4: What is the percentage of participants who currently have a 504 Plan or an Individualized Education Program (IEP) in place?

Research Question 5: How similar or dissimilar are the rank-ordered lists of given accommodations and the ideal accommodations?

**Significance of the Study**

The present study is significant due to the fact that pediatric patients with systemic lupus erythematosus have a life-threatening illness, but it is currently not known what type of assistance would best support these pediatric patients in the school setting. The disease activity of lupus is most severe during the adolescent years, so every precautionary effort should be attempted during this time period for the sake of survival. Because middle and high school are challenging enough in various psychosocial and academic ways, adequate support has the potential to mitigate patients' stress level, thereby easing disease activity.

By having patients self-report their preferences through a survey, determining the best accommodations can come directly from the patients' own experience. Compiling their preferences would allow the medical and educational community to gain a greater understanding of which accommodations may be most beneficial for implementation in the school setting.
Chapter Two: Literature Review

Introduction to Systemic Lupus Erythematosus

The medical diagnosis of “systemic lupus erythematosus” was coined from a combination of Latin and Greek terminology (Boston Children's Hospital, 2019). "Lupus" comes from the Latin translation of the word “wolf,” while "erythema" is the Greek word for "red." Rogerius, a 13th century physician/researcher, selected the name based on observations of reddish facial lesions on patients’ noses and cheeks (Lupus Foundation, 2020). The lesions reminded him of bite marks from a wolf. In modern times, that malar rash is described by physicians as being a "butterfly rash", due to its butterfly-shaped presence on the nose and cheeks (Coughlin, 2019). Approximately 30% of patients with systemic lupus erythematosus have the distinctive, butterfly-shaped rash (Coughlin, 2019). Some patients may also exhibit discoid rashes, which are irregular red rashes that may be found on the chest or neck (Kidshealth, 2019).

The word "systemic" is included in the diagnosis, because the illness may impact various organs within the human body (LFA, 2020). It has the potential to affect any organ system within the human body (Lindsey, 2020). Personal variation can occur within each affected organ, as well as variation in the severity of the autoimmune response. Such a wide variety of manifestations can make it difficult for physicians to produce an accurate diagnosis, which is why a correct diagnosis of lupus can take almost six years, on average, for adults (LFA, 2016). Approximately 63% of patients were given incorrect, initial diagnoses prior to the correct lupus diagnosis (Maloney, 2015).

Systemic lupus erythematosus (known as SLE or simply "lupus") is classified as an autoimmune illness, which is under the umbrella of rheumatological conditions. On the
“MedicineNet” website, "autoimmunity" is medically defined as a "misdirected immune response that occurs when the immune system goes awry and attacks the body itself" (Shiel, 2018). The immune system attacks its own healthy cells, tissues, and organs within the body, instead of guarding them from disease.

The Lupus Foundation of America (2020) reported that the cause and cure for the autoimmune condition remains unknown. The most common hypotheses for the lupus phenotype include issues involving hormones, the environment, and genetics (LFA, 2020). A genetic predisposition to lupus may be activated by something outside of the body. Both internal and external factors interplay in a manner that has yet to be understood. For example, Temple University scientists found that bacterial communities and an abnormal protein can contribute to the exacerbation of lupus (Mayo Clinic, 2018).

Lupus is a life-threatening condition that is marked by cyclical, unpredictable periods of remission and flare-ups, and medical risk is greatest during the flares. Each period of remission or flare may vary in terms of the symptoms, timeframe, and severity. The greatest danger of lupus occurs when one or more of the patient’s vital organs are under siege by the immune system. Medical complications may occur during this process of treating lupus and treating the affected organ. Consequently, other medical specialists are often needed for collaboration during flare periods.

Kidneys are most commonly attacked in lupus (lupus nephritis), and it is no longer uncommon to require kidney transplants to replace the damaged ones. Kidney complications occur in approximately 60% of lupus patients (Metelski & Rovin, 2017). Some hospitals combine a lupus clinic with a nephrology clinic, so that kidney complications can be caught and monitored early in the disease process.
Factors which can contribute to the increased possibility of entering a flare state involve having too much physical stress, emotional stress, or overexposure to the sun (Iliades, 2015). Thus, lifestyle changes are usually necessary in order to avoid a lupus flare. Some flares manage to occur without any warning symptoms (LFA, 2020). Consequently, the unpredictable nature of the illness requires close monitoring by the treatment team.

**Types of Lupus**

The American College of Rheumatology has distinguished four different types of lupus. They include: cutaneous/discoid lupus erythematosus, drug-induced lupus erythematosus, neonatal lupus, and systemic lupus erythematosus. Cutaneous lupus is also known as "discoid lupus erythematosus", and it produces skin discoloration and atypical skin issues as a result of the immune system attacking the skin (Eastham & Vleugels, 2014).

Drug-induced lupus is a condition which matches its name. Lupus can be induced by certain medications, but the effects are temporary. Those medications which can initiate lupus-like symptoms are starting to be shunned as other medicinal alternatives become available. Young patients may experience joint pain, severe fatigue, and fever. However, this form of lupus often does not affect the vital organs, which the traditional form of lupus can do. Symptoms of drug-induced lupus will usually disappear within a few weeks after the triggering medication is discontinued (Boston Children’s Hospital, 2019). Some anticonvulsants may have this effect of mimicking lupus symptoms.

Neonatal lupus is a form of lupus that can affect the babies of women with certain antibodies. Approximately 40% of the mothers who have children with neonatal lupus erythematosus, have lupus themselves (Johns Hopkins Medicine, 2020). With neonatal lupus, the auto-antibodies impact the baby through the placenta, and the impact usually ends within the first
several months of the infant's life. The auto-antibodies eventually disappear from the infant's immune system. The condition is dangerous due to the possibility of leaving permanent cardiac damage in the infant (Johns Hopkins Medicine, 2020).

Because systemic lupus erythematosus is the most common and most dangerous form of the illness, the present study will focus on the systemic phenotype rather than the other types of lupus (Lindsey, 2018). Approximately 70% of lupus patients have the systemic type of lupus, which carries the greatest risk to the organs and to the lives of affected pediatric patients.

**Incidence and Prevalence of Systemic Lupus Erythematosus**

In order to fully understand the proportional magnitude of autoimmunity, current statistics may shed light on its prevalence within the United States. The National Institutes of Health estimates that 23.5 million individuals have some form of an autoimmune disease (AARDA, 2018). For the sake of comparison, heart disease affects 22 million individuals, and cancer impacts 9 million patients (AARDA, 2018). The Lupus Foundation estimates that 16,000 new pediatric and adult cases are diagnosed each year (LFA, 2016).

The Center for Disease Control (CDC) acknowledges that autoimmune illnesses are "on the rise", but no valid reasons for this phenomenon could be offered, because they remain unknown (Rattue, 2012). Yen et al. (2018) found that SLE was the leading “chronic inflammatory disease, ranking higher than diabetes mellitus, human immune deficiency virus disease, chronic lower respiratory disease, nephritis, pneumonitis, and liver diseases,” in young women who are between 15 and 24 years of age.

The Lupus Foundation of America estimates that approximately 1.5 million Americans and 5 million individuals worldwide have systemic lupus erythematosus. The highest incidence of lupus is in North America, which may possibly be due to the accuracy of diagnosis rather than
the true prevalence of the illness (Rees, 2017). The lowest incidence of lupus was found in Ukraine, Africa, and northern Australia. Lupus also appears to be more common in urban areas than in rural areas (Schur & Hahn, 2020).

The link of lupus with urban environments was found in a study conducted in Brazil. Researchers discovered that air pollution was "strongly associated" with pediatric lupus activity (Ammam, 2016). The study prompted Dr. Maria Fernanda Goulart, Department of pediatric Rheumatology at the University of Sao Paulo to state in a news release: "Our findings have shown that air pollution doesn't just increase the incidence and prevalence of chronic lung disease and acute respiratory infections. It is also an important contributory factor in childhood rheumatic diseases, such as lupus" (EULAR, 2016). She also stated that "with air pollution increasing in many major cities, pediatric rheumatologists can expect to see a resultant impact on the disease activity of their lupus patients" (EULAR, 2016).

As for the statistics among patients who are under the age of 18, the Arthritis Foundation estimates that approximately 25,000 children and adolescents have lupus or a related disorder (Children’s Hospital of Philadelphia, 2019). Another estimate proposed that 30,000 children and adolescents are affected (Onel, 2018). Childhood-onset lupus is estimated to equal approximately 15 to 20% of all lupus patients (Nationwide Children's Hospital, 2017).

As for the incidence of lupus among children under 18 years of age, it ranges from .36 to 1 per 100,000 children (Nabors et al., 2015). The prevalence rates of pediatric SLE is 4 to 250 cases per 100,000 individuals. One statistic showed that African-American children comprised 60% of all SLE patients under the age of 20 years old. The high prevalence of lupus among African-American children matches the prevalence among the adult lupus population (Iliades, 2009).
Diagnostic Criteria of Pediatric Systemic Lupus Erythematosus

The criteria for the diagnosis of lupus have been revised a few times throughout history as we gain a greater understanding of the disease. Lupus is a very challenging illness to diagnose, even among the most skilled of physicians. The reason for the difficulty is due to its mimicry of other illnesses (New York State Department of Health, 2015). The symptoms of lupus can often be subtle and easily overlooked by general practitioners. Lupus often mimics other conditions, which is why the Lupus Foundation calls the illness "the great imitator" (LFA, 2016). For example, the butterfly rash on lupus faces may not be dramatically visible. The time that is lost during the search for a diagnosis may further impact affected organ(s), which impacts the patient’s prognosis. Rekvig and Van der Vlag (2014) wrote that questions outnumber answers regarding the etiology, diagnosis, and treatment of lupus. Consequently, subtle features and symptoms may not be easily recognized.

The American College of Rheumatology established 11 specific criteria to guide physicians when considering a lupus diagnosis (Paz, 2017). Due to the variability of organ involvement and wide-ranging spectrum nature of the illness, a patient is not required to exhibit each of these symptoms. The American College of Rheumatology and the Lupus Research Alliance reported that children must have 4 of the 11 criteria before a diagnosis can be made.

The eleven specific criteria include:

1. Skin rash – raised red patches or bumpy skin
2. Photosensitivity – sun light can exacerbate the illness, causing increased disease activity
3. Mouth or nose ulcers – usually observable but painless
4. Nonerosive arthritis – inflammation or pain in two or more joints.
5. Cardio-pulmonary involvement – inflammation of the heart lining and/or lungs
6. Neurologic disorder – seizures and/or psychosis
7. Kidney disorder – increased protein in urine sample or clumps of red cells
8. Blood disorder – anemia (inadequate hemoglobin) caused by damaged red cells, low white cells or low platelet count
9. Immunological disorder – when the immune system attacks healthy cells, autoimmune activity
10. Antinuclear antibodies (ANA) – positive blood test not induced by drugs or other chemicals
11. Malar rash – a rash across cheeks and nose which resembles a butterfly

**Gender and Racial Differences**

Gender is a significant factor in the incidence and prevalence rates of lupus, because lupus strikes females 8 to 15 times more than males (Murphy & Isenberg, 2013). The women who are affected are usually within their child-bearing years, between the ages of 12 and 44 when they are diagnosed. Interestingly, during childhood, the ratio of females to males are not as disproportional as during adulthood (Lo, 2018). Because of that fact, hormones are hypothesized to play a role in the progression of the disorder.

Iliades (2009) described a pattern of ratios through a longitudinal lens by stating that adult females outnumber adult male patients by 10:1. Among pediatric patients, females outnumber male patients by 4:1. Males appear to be affected more during their childhood years than during the adult years (Iliades, 2009). According to other statistics, the female to male ratio has been estimated to be 4:1 before puberty and after menopause. The female to male ratio can rise to 8:1 during the child-bearing period between menarche and menopause (Klein-Gitelman,
Such findings are the reason why researchers are examining hormonal influences in the activation of the disease. It is not entirely known how the effects of puberty impact autoimmunity and its pathophysiology (Ardoin & Schanberg, 2012).

In terms of race, lupus tends to strike minorities at a significantly higher rate than those of Caucasian/European descent (Jewitt-Tenant, 2017). The prevalence of lupus in African-American, Hispanic, and Asian women are all significantly higher than Caucasian women. As for Native Americans, they are often diagnosed with lupus at a younger age and present with more severe symptoms than other ethnic groups (Mumal, 2018).

Among pediatric patients with lupus, Hiraki et al. (2009) reported that 60% of the 265 patients in their study cohort were non-Caucasian. Non-Caucasian patients, especially those who are African-American, were younger at diagnosis than Caucasian patients (12.6 years vs 14.6 years, \( p=0.007 \)). Non-Caucasian patients were also more likely to have lupus nephritis (62% vs 45% \( p=0.01 \)) (Hiraki et al., 2009). Mina and Brunner (2010) also reported "large variations" involving lupus nephritis among the different races. It is unknown why minority patients’ kidneys may be more affected.

**Morbidity and Mortality**

Although lupus is viewed as a chronic illness, death remains a possibility, and it is highly dependent on disease activity. UCLA researchers analyzed mortality statistics from the Centers for Disease Control and Prevention from 1968 to 2013 and compared them with data from the U.S. Census Bureau. A comparison of the data showed that the lupus mortality rate did not decline as much as it did for the overall population (Yen et al., 2017). Increased rates for lupus patients were reported during the 1970’s and 1990’s, but mortality decreased overall since 1968, even among African-American patients (Yen et al., 2017).
Medical advances have extended the lives of patients with lupus, but childhood-onset lupus tends to have higher mortality rates (Walsh, 2010). Because the disease appears to be more active during this period, the overactivity can lead to organ damage which can lead to death. Rubinstein et al. (2015) noted that renal failure is a leading contributor to morbidity, but neuropsychiatric issues are an equally, if not more, significant contributor to morbidity. Survival for pediatric patients with lupus nephritis now exceeds 90% (Wenderfer et al. 2016). Cardiovascular disease and infections also contribute to premature death (John Hopkins, 2019). A recent study indicated that childhood-onset lupus had "an over 4-fold higher rate of pericarditis/myocarditis” compared to adult-onset SLE” (Chang et al., 2018, p.2151). The American College of Rheumatology questioned if death certificates underestimated the mortality rate of “rare diseases” in Sweden (Falasinnu, 2017). Because the cause of death may be attributed to organ complication(s) instead of the root illness of lupus, the death certificate may not state lupus as the primary cause of death. For example, "kidney failure" may be listed on the death certificate rather than the cause of the kidney failure, namely lupus nephritis. Thus, the statistics regarding the number of deaths may be skewed. UCLA researchers confirmed this hypothesis in America when they found that lupus is often not included on death certificates. Consequently, the lupus mortality rates may not be accurate (Franki, 2018).

Hollander et al. (2013) reported that increased mortality is associated with pediatric lupus rather than with adult-onset lupus, and adults with childhood-onset lupus carry a greater mortality risk than those with adult-onset lupus (Walsh, 2010). More disease damage has also been documented among young patients. Cumulative organ damage was observed in approximately 50% to 60% of pediatric patients, which contributes to the increased impact of the
disease on the body (Ravelli, 2005). It is known that approximately 10% of children will not survive ten years after their lupus diagnosis (Ravelli, 2005).

Lupus was described as "quietly killing young women" after it became the 10th leading cause of death among young women between 15 and 24 years of age (Franki, 2018). It was also the 14th leading cause of death for women who are between 25 and 44 years of age (Franki, 2018). The racial disparities are also evident through the higher mortality rates among minority women in general (Alarcon et al, 2006).

The 5-year and 10-year survival rates are comparable between pediatric and adult onset lupus. Tektonidou et al. (2017) reported that the survival rate among children during the span of years between 2008 and 2016 is statistically significant when comparing those from high-income and low-income countries, and that 5-year and 10-year survival rates were lower among pediatric patients than adult patients in low to middle-income countries. Pediatric patients from middle to low-income countries had a lower survival rate than adults from those same countries (Tektonidou et al., 2017). Similar socioeconomic differences exist in both adult and pediatric patients, based on studies from 1950 to 2016 (Tektonidou et al, 2017). High-income countries produced 5-year survival rates which exceed 95% in both adult and pediatric patients.

Despite steady improvement, lupus survival appears to have peaked during the mid-1990s (Tekonidou, 2017). These findings stem from 125 studies on adult patients and 51 studies on pediatric patients. During the time frame between 2008 and 2016, the 5-year, 10-year, and 15-year lupus survival rates appears to have gradually decreased. The same pattern was found for pediatric patients during those same years. That pattern remained consistent regardless of the income of the patient. Brunner and Gitelman (2009) acknowledged that there are access issues for certain individuals due to limited coverage by insurance companies. That fact may explain
the difference in mortality rates, when one compares the coverage of the various ethnic groups of patients.

A large, international study on lupus revealed that deaths during the years of 1958-2001 were more likely to occur if certain complications are involved (CDC, 2018). They include: active disease, organ failure, infection, or cardiovascular disease relating to atherosclerosis. In addition, lupus-related deaths were more frequent among young females who have had the illness for a relatively short amount of time. In 2002, the CDC issued a report stating that lupus deaths increased above the preceding 20-year period, despite some limited medical advances (CDC, 2018).

The increase was most evident among African-American women between the ages of 45 and 64 years. The fatality rate of African-American lupus patients is usually three times higher than Caucasians (CDC, 2002). According to data gathered in the state of Georgia from 2002-2016, the incident mean age at death for African-Americans was 51.8 years while Caucasians equaled 64.4 years (Lim et al., 2019). Neurological complications, hemorrhage, and stroke tend to occur more frequently among African-American patients. However, kidney failure and cardiac issues are more common among Hispanic women (CDC, 2002). African-Americans had a significantly persistent higher rate of mortality starting from their initial diagnosis, and gender did not reveal any significant differences (Lim et al., 2019).

In an attempt to address and explain the racial disparities, numerous researchers united in 1993 to examine the nature and nurture aspects of lupus. Their efforts came to be known as the LUMINA ("Lupus in Minorities") study (Jewitt-Tenant, 2017). The most crucial findings from ten years of data indicated that poverty and lack of access to healthcare are key contributors to the increased likelihood of mortality among minorities.
Although the findings are relevant to the understanding of lupus in adults, their value and application can be extended to pediatric rheumatology. By knowing the specific groups who are at highest risk for mortality from lupus, research can focus on the corresponding pediatric population for the sake of early identification and preventive treatment.

**Childhood-Onset Lupus**

It has been documented that childhood-onset lupus is associated with more severe disease activity and impairment than adult-onset lupus (Tunnicliffe, 2015). Young patients with lupus experience more cardiovascular, renal, and neuropsychiatric issues than adult patients (Tunnicliffe, 2015). The treatment options are very similar to adult lupus patients, so young bodies must be treated with powerful immunosuppressant medications, which increases their risk of additional medical complications. When the immune system attacks the organs, organ damage and comorbid complications can occur. The disease activity, the comorbid complications, and the adverse side effects from medications combine to impede the young patient from living a "normal childhood".

Approximately 10 to 20% of patients experience the onset of systemic lupus erythematosus during adolescence or childhood. From a biomedical perspective, early presentation of the disease symptoms may also indicate a strong genetic contribution (Lo, 2018).

In 2013, the first international consensus (involving the United States, India, Brazil) on indicators of pediatric systemic lupus erythematosus was reached (Mina et al., 2015). As expected, there were numerous similarities with adult markers of systemic lupus erythematosus. However, specific patterns of disease activity were more apparent among childhood-onset lupus than adult-onset lupus, and they were incorporated into the diagnostic profile (Mina et al., 2015).
Hedrich et al. (2017) found that the inflammatory symptoms of systemic lupus erythematosus manifests in 10-20% of patients under 16 years of age.

The most frequent symptoms that pediatric lupus patients display are fever, fatigue, and weight loss. The most common organ-related impact that the disease can have on the body includes distress on the skin, kidneys, and musculoskeletal system (Thakral & Klein-Gitelman, 2016). The age of lupus onset is important in determining the type of challenges that may be present in the future. After examining the various quality indicators for pediatric lupus care, it was found that other countries, outside of the United States of America, could not meet "evidence-based minimum standards of medical care" (Thakral & Klein-Gitelman, 2016). The lack of care contributes to further complications and increased morbidity.

The prognosis for pediatric patients depends on the level of individual organ involvement. Special attention must be given to pediatric lupus patients with the following disease factors (Thakral & Klein-Gitelman, 2016):

a. High dose glucocorticoid therapy (man-made versions of naturally occurring steroids within the body) during the initial diagnosis
b. Antibody profile testing
c. Adequate ophthalmological examinations (since a key lupus medication, hydroxychloroquine, may damage the retina)
d. Symptoms of lupus nephritis
e. Pharmacological safety

**Pediatric Systemic Lupus Erythematosus**

Due to the wide spectrum of symptoms, no single test has been identified to pinpoint a diagnosis of lupus. Physicians base their diagnosis on the child's medical history, current
presenting symptoms, a thorough physical examination, and various diagnostic tests and/or scans. Examples of the various tests include blood tests to examine specific antibodies, urinalyses to investigate kidney functioning, and x-rays to assess internal organs and bones.

As for the specific tests that are closely scrutinized on blood tests, rheumatologists usually examine several key factors. One of them is the erythrocyte sedimentation rate, commonly known as the ESR or "sed rate". That test measures the rate at which red blood cells fall to the bottom of a test tube. When cells are inflamed and swelling, the red blood cells become heavier than normal, which allow them to fall faster to the bottom of a test tube.

The C-reactive protein is another commonly examined factor because it is indicative of the amount of inflammation in one's body. Inflammation is a key factor in autoimmune disease progression. Protein complements are also important when assessing disease activity. They are a group of proteins within the blood that assist with the destruction of foreign substances (Janeway et al., 2001). The system of complements helps to defend the body from infection (Janeway et al., 2001).

**Treatment for Lupus**

Even though there is no cure for lupus, there are certain treatments that can alleviate some of the symptoms. The factors that determine the proposed treatment involve the patient’s age, health history, tolerance for certain medications and therapies, affected organs, and the extent of the autoimmune activity.

It is a challenge to treat an illness whose etiology and biological processes are not fully comprehended. Treatment options are very limited for both adult and pediatric patients. The choice of treatment depends on the presenting symptoms and severity of disease activity.
Additional medications may be prescribed as other complications arise. The list of possible ways to treat lupus include:

- Non steroidal anti-inflammatory drugs (NSAID)
- Hydroxychloroquine
- Corticosteroids (e.g. prednisone, prednisolone, Medrol)
- Other types of immunosuppressive medications (e.g. cyclophosphamide, methotrexate)
- Monoclonal antibodies
- Consistent use of sunscreen and avoidance of the sun
- Adequate rest and stress reduction strategies
- Well-balanced (sometimes low sodium) diet
- Other medications for specific infections or organ complications.

The pharmaceutical treatment options for lupus all have potentially serious side effects. Corticosteroids were first introduced by Hench, and the Merck company began to mass produce this key lupus medication in 1948. Corticosteroids include medications such as prednisone, prednisolone, and methylprednisolone. This family of medications has severe side effects, which include a significant swelling of the face (also known as “moon face”), hypertension, osteoporosis, weight gain, increased vulnerability to infection, easy bruising, and muscle weakness. Corticosteroids also impact memory and mood, and may contribute to changes in the hippocampal structure (Brown et al., 2004). Despite the serious side effects, corticosteroids are effective for calming inflammation and alleviating lupus-related symptoms (LFA, 2020). Corticosteroids have been described as being "a metaphorical double-edged sword" due to its healing properties and adverse side effects (Drosdowicz & Bostwick, 2014).
In addition to corticosteroids, treatment options include anti-malarial medications, such as Plaquenil (hydroxychloroquine), and cytotoxic/immunosuppressive agents, such as Cytoxan (Hochberg & Alarcon, 2017). Chemotherapy is administered in life-threatening cases of lupus. The latest treatment option among adult patients involves the use of a hormone called dehydroepiandrosterone (DHEA), but its benefits are debatable, according to researchers (Sawalha, 2008). This hormone was found to increase when patients are in a mode of relaxation, as opposed to the release of cortisol when patients are in a stressful state of mind. In 2011, the Federal Drug Administration approved a medication for lupus called belimumab (Benlysta). This was the first medication to be approved for lupus in over 50 years (CDC, 2018).

Medication compliance is a major concern among lupus patients. A systematic review of 11 studies involving self-reported information revealed that over half of lupus patients are not taking their medications as directed by their physicians. Antimalarial medications had one of the worst compliance rates among lupus patients (Pharmaceutical Technology, 2017). These medications offer long-term benefits without marring the patient’s appearance or functioning, as corticosteroids usually do. The primary adverse side effect of the medication is that a very small percentage of patients may experience retinal toxicity (Pharmaceutical Technology, 2017). That is why regular ophthalmological monitoring is required for those who are on a daily regimen involving hydroxychloroquine, the most commonly prescribed anti-malarial medication.

**Consequential Side Effects and Complications from Treatment**

Dr. Emily von Scheven (2020) reported that better treatments are being developed for pediatric lupus cases, but physicians are finding that there are secondary complications. These complications can sometimes be as serious as lupus itself. That is why this chronic illness requires multi-faceted, precautionary monitoring. For example, hospitalized infections were
found to be common among children with lupus (Hiraki, 2017). These infections can be
bacterial, viral, or fungal. Children who ingest corticosteroids have higher infection rates than
those who do not, because they suppress the immune system (Hiraki, 2017). Further, because
children require vaccinations, children with pediatric lupus should not receive immunizations
with live viruses. These types of live vaccinations include the chicken pox vaccine, measles,
mumps, rubella, and oral polio vaccines.

Corticosteroids may also impede children’s height. A study conducted by Heshin-Bekenstein (2019) found that pediatric lupus patients were 2.4 centimeters shorter on average
than their peers. The reason for the disparity in height involves the onset of lupus during puberty,
which coincides with the period when children grow the most. There are numerous possibilities
to explain the height differences, with one of them being side effects from the corticosteroids.
Bandeira et al. (2006) found that discontinuing corticosteroid treatment resulted in some “catch up growth.”

**Pain Management**

Pain management may require some psychological intervention, in addition to medical
intervention (Nabors et al., 2015). Although there are limited studies with children, physicians
generally endorse the use of pain-alleviating strategies for adults to be used with children. Prior
to the implementation of pain interventions for children, it is recommended that a thorough
explanation be provided to them for their understanding. Three strategies were mentioned by
Nabors et al. (2015). They include cognitive-behavioral therapy, the elimination of negative
thoughts, and relaxation techniques.

Hui et al. (2017) found that cognitive-behavioral therapy can be successful at alleviating
pain and depression in adults. Neurocognitive dysfunction can change or be persistent over time.
Risk factors are not completely understood, but a longitudinal study of 123 multi-ethnic adults with SLE, known as the "Salud" study, revealed that a higher level of depression is associated with neural cognitive dysfunction (McLaurin et al., 2005). The elimination of negative thoughts can be achieved through several methods, including slower breaths or deep breathing, muscle relaxation, and thought replacement strategies. With these types of strategies, adults were found to experience decreased stress, depression, and overall pain. Similar relief can be expected for children as a means of alleviating their pain and helping them function in school (Nabors et al., 2015).

**Prognosis for Pediatric Patients with Systemic Lupus Erythematosus**

Due to the fluctuating spectrum nature of disease activity, absolute certainty from rheumatologists regarding each patient’s prognosis is not possible. The prognoses of pediatric patients with systemic lupus erythematosus is highly dependent on the level and the type of organ involvement that is impacted (LFA, 2013). On July 1st, 2019, the Childhood Arthritis and Rheumatology Research Alliance (CARRA) and the Lupus Foundation of America prioritized lupus nephritis and neuropsychiatric disease as the two most "urgent, unmet needs in childhood onset lupus."

Key variables in SLE patient outcomes include "hospitalizations, disease activity, disease damage, mortality and quality of life" (Lawson & Yazdany, 2012, p. 96). The LUMINA study concluded that organ damage and poverty were significant predictors of mortality among adult patients (Bertoli et al., 2008). The organ that is involved will be a significant factor in the level of disease severity, which would then help predict morbidity or mortality (Lim et al., 2014). In general, lupus is a chronic illness where the majority of patients do survive if proper health maintenance measures, such as medication compliance and avoidance of ultraviolet light, are
followed consistently. With the longer lifespan than in the past, there are more pediatric patients living with more disease activity and accrued damage within their bodies (Aggarwal & Srivastava, 2015).

**Cutaneous Problems**

There are three types of cutaneous, or skin, problems involving pediatric systemic lupus erythematosus. They include acute, subacute, and chronic cutaneous disorder (Eastham & Vleugels, 2014). Acute cutaneous lupus consists of redness across the nose and cheeks, which is the “butterfly rash.” Subacute cutaneous lupus involves a red and scaly rash across sun-exposed areas of the body. Chronic cutaneous lupus consists of red and purple rashes and scars, and it may also include patches of hair loss and scarring in the bowl of the ear.

Sunlight exacerbates all three types of cutaneous lupus. Consequently, cutaneous issues present as an issue that must be addressed in the educational plan of the child, because physical education requirements, which usually occur outdoors, may exacerbate the illness. Being in the sun increases the risk of lupus flare-ups, so accommodations may be necessary in order to limit ultraviolet light exposure.

**Lupus Nephritis**

Lupus nephritis is a condition involving inflammation of the kidneys due to lupus involvement (Walsh, 2018). It affects a "significant proportion" of children with lupus, and it is the "most important predictor of morbidity and mortality" (Thakur et al., 2017). It also accounts for approximately 60% of pediatric hospitalizations involving lupus (Walsh, 2018).

Our understanding of lupus nephritis has changed dramatically over the past 50 years (Wenderfer et al., 2016). Rheumatologists are updating their treatments as research constantly updates the strategies to keep the kidneys of young patients intact. Between 50% and 75% of
pediatric patients with lupus experience lupus nephritis, or lupus with kidney involvement (Sinha & Raut, 2014). A meta-analysis shows that pediatric patients with systemic lupus erythematosus have a 10%-30% higher prevalence of developing kidney involvement than in adults, which is why pediatric rheumatologists monitor the kidneys closely (Wenderfer et al., 2016).

Kidney biopsies are a means of gaining accurate information on the child's renal functioning, and the results are much better interpreted than in the past. Children usually undergo kidney biopsies under general anesthesia, while adults are locally sedated around the kidney site. Three measures that are often used to assess kidney function include creatinine, urinalysis, and glomerular hematuria (a key symptom of kidney disease). Wenderfer et al. (2016) reported that these measures can be inaccurate, which is why a kidney biopsy is recommended for absolute certainty regarding the level of impairment.

Cyclophosphamide, a type of chemotherapy, is often added to the treatment regime in order to manage lupus nephritis (Sinha & Raut, 2014). The issue regarding access to medical care is most evident in regards to renal transplantation (Hiraki et al., 2011). Kidney disease relating to lupus nephritis accounts for 1.9% of all end-stage kidney disease patients (Sabucedo & Contreras, 2015).

Cardiovascular Disease

Cardiovascular disease is the "number one cause of death" among all lupus patients combined (Johns Hopkins, 2019). Lupus patients often experience an increased and premature risk for atherosclerosis, where fatty substances progressively deposit on the inner artery walls (Fogoros, 2018). They are also found to have cardiac abnormalities (Gunal et al., 2003). Children born to women with lupus were found to have a higher rate of congenital heart defects too (Vinet
et al., 2014). Premature atherosclerosis is a significant factor in mortality and morbidity in children (Sandborg et al, 2008).

Inflammation is a key indicator of possible atherosclerosis. For that reason, dietary changes must be established in order to prevent additional risk factors to the already elevated risk for the pediatric patient (Sandborg et al., 2008). Questions remain as to whether additional cardiovascular treatments are necessary in order to decrease that risk even more.

**Multidisciplinary Care**

Rheumatologists are usually the primary specialists who treat persons with lupus. Rheumatology involves the treatment of a variety of autoimmune disorders, such as rheumatoid arthritis and fibromyalgia. The variability of lupus requires rheumatologists to collaborate with other medical specialists in the management of the disease. Ardoin and Schanberg (2012) stated that youngsters with lupus require "specialized, multidisciplinary care." The specialties that are most commonly involved with lupus patients include nephrology, neurology, cardiology, immunology, and hematology. Due to the lack of research on the epidemiology and management of lupus, current best practice treatment is multifaceted, so there is constant collaboration and communication among a treatment team of physicians. In addition to the physiological aspects of disease management, youngsters also require attention to be devoted to the developmental/psychosocial aspects of their functioning.

**Transition of Care**

Due to progress regarding improved survival rates, medical maintenance must be established with a long-term perspective that can help patients transition medically and developmentally. The transition from pediatric lupus to adult lupus care is a crucial process due to the severity of the illness. Son et al. (2016) called for more studies to examine adolescent
patients' transition from being under the care of pediatricians to adult physicians. Son et al. (2016) examined this critical transition of providers, and found that depression and anxiety increased significantly during the transition, from 10% to 26%. Contributing issues, such as depression, fluctuating mood, health perceptions, and self-esteem, can negatively impact the disease process.

The challenge of transitioning is evident through the gap of time between the last pediatric provider to the new adult provider. According to Son et al. (2016), non-adherence to treatment plans also has the potential to have dire consequences. Fredericks et al. (2008) stated that special considerations must be made as the receiving rheumatologist adjusts to the medical and socioemotional issues presented by the new patient. The young adult patient must learn to make medical decisions and navigate his/her own healthcare independently. Those who are entering young adulthood may find that navigating the adult world of healthcare can be a challenge. Thus, it is important to be mindful of the age of the pediatric patient and the circumstances surrounding not only the medical aspects of their care, but the psychosocial and educational aspects of their care as well.

The transition process was examined by researchers in Italy in a study of 25 patients diagnosed with pediatric lupus (Costagliola et al., 2018). Longitudinal data were collected for approximately eight years. The most remarkable finding from this study centered on the evolution of the disease progression. Pediatric patients who exhibited chronic organ damage had more disease activity during the follow-up when prescribed a significantly higher dose of corticosteroids. The authors suggested that pediatric patients with immune cytopenia (when the level of a blood cell type is lower than it should be) require more "strict clinical follow-up for the
risk of evolution to lupus" (Costagliola et al., 2018). They also emphasized the need for "intense surveillance of renal function."

Sadun and Schanberg (2017) recommended having a "transition coordinator" to bridge the treatment transfer in order to ensure continuity of care and the need for developing the patient's self-management skills and ongoing medication compliance during the process.

**Access to Quality Health Care**

As mentioned earlier, one of the contributing factors to the outcomes of a disease such as systemic lupus erythematosus involves access to healthcare. It is important to note that adequate healthcare must be differentiated from quality healthcare. The Arthritis Foundation reported that the number of rheumatologists is expected to decline over the next decade (Davis, 2020). The 5,415 rheumatologists who were registered in 2015 is projected to decrease to 4,051 rheumatologists by 2030. The number of rheumatology medical students is not large enough to fill in for the number of rheumatologists who are preparing to retire over the coming years.

Because there are more rheumatologists in metropolitan areas, patients residing in smaller, rural areas may not be able to have the same level of medical care. Because of the multi-organ impact of lupus, patients usually must have a multi-disciplinary team involving numerous specialties to monitor multi-organ involvement. Thus, the necessity of living in an area with access to a wide variety of medical specialists places extra constraint on the patient's ability to access adequate comprehensive patient care.

Lawson and Yazdany (2012) listed possible factors that can directly or indirectly impact patient outcomes. Insurance coverage is a major factor in both the adequacy and quality of care. Insurance companies have the authority to make administrative decisions that may permit or deny various forms of treatment which can ultimately benefit the patient. The LUMINA study
alludes to the significant differences in mortality rate by identifying the specific factors of insurance coverage and socioeconomic disadvantage (Bertoli et al., 2008).

**Psychological Effects of Chronic Illness**

Although an illness such as lupus prompts experts to think of the etiology and immunological processes from a purely scientific and medical perspective, a recent study offers a unique psychological perspective. A recent study resulted in a strong association between the exposure to trauma (with or without a formal diagnosis of Post-Traumatic Stress Disorder) and an increased risk of having lupus among adult patients (Roberts et al., 2017). A sample of 54,763 women were screened and the hazard ratio was 2.83 (95% CI 1.29-6.21, \( p < 0.01 \)). Childhood trauma has also been linked to lifelong chronic illness in the Adverse Childhood Experiences study (Nakazawa, 2016).

In this study of over 54,000 women, those who experienced a traumatic event had a two-fold higher risk for lupus than those who did not. Those who displayed symptoms of Post-Traumatic Stress Disorder had a three-fold risk. Stress, in general, has been recognized as contributing to flare-ups of the illness. The psychoneuroimmunology behind this complex illness needs to be practically examined in children and adolescents due to the potentially stressful environment of school. Illness can affect interactions with teachers if an incorrect perspective is fostered. For example, teachers may not understand the severity of the illness and assume that the child is lazy and/or incapable.

In addition to monitoring the cognitive development of pediatric lupus patients, it becomes necessary to monitor the psychosocial burdens (Levy, 2012). Proper psychological and educational support must be factored into a holistic treatment plan. As for the psychosocial burdens of pediatric patients with lupus, coping with a chronic illness may be challenging for
patients within this age range. The regular challenges of trying to achieve in school and fitting in among peers is complicated by factors such as pain/discomfort and medication side effects. Having relationships with one's peers facilitates the growth of self-esteem and a sense of acceptance and belonging (Rubin & Bukowski, 2011). Rhee et al. (2011) found that peer support helped to generate more positive attitudes in pediatric patients with lupus.

The interwoven issues involving family and the acceptance of a chronically ill self can complicate the disease process (Iliades, 2015). As for psychosocial burdens, it is important to remember that chronic illness is challenging for any patient, but those in this age range must face the additional challenges of sickness on top of typical adolescent struggles. Such struggles can develop into serious complications within the disease process (Iliades, 2009). Resilience is the aim for each patient, both in medicine and in education. Tunnicliffe (2016) discussed various aspects of medical resilience for adolescents, including the following factors: gaining personal independence, developing self-reliance, adjusting the perceived disease activity and/or ability, dependence on others, and trusting the physicians who are their primary providers.

The effects of chronic illness on a child has been shown to foster depression and isolation (Levy & Kamphuis, 2012). That is why the Lupus Foundation of America recommends that pediatric patients be asked regularly about how they are feeling because they may need extra psychological assistance, such as professional therapy. In the medical setting, medical social workers are available to check in with patients. However, patients need to find affirmation of their self-worth and value from teachers and parents as well (LFA, 2019).

A major factor that makes lupus patients more prone to “adverse psychological side effects” is the use of corticosteroids as the main strategy for immunosuppression (Stuart et al., 2005). Corticosteroids can cause labile mood, anxiety, and irritability (Warrington & Bostwick,
Kohut et al. (2013) reported that among children and adolescents, prednisone dosage was found to be associated with negative self-esteem and somatic depressive symptoms. Few studies have been conducted on these specific variables in childhood-onset systemic lupus erythematosus.

Davis et al. (2018) examined the potential relationship between depression and medication non-adherence. Demographics and disease characteristics were taken into account during the analysis. The results from 51 questionnaires revealed that 58.8% experienced depression. Seven patients revealed suicidal ideation, which accounted for 13.7% of the sample. Patients who were willing to self-report their medication non-adherence equaled 19.7% of the sample. No statistical differences were found among various demographic and disease characteristics. Those who reported medication non-adherence were more likely to have longer disease duration. The authors found that as the depressive symptoms increased, the degree of medication non-adherence also increased. Consequently, there appears to be an important association between depression and medication non-adherence in childhood-onset systemic lupus erythematosus.

Because of the medications' impact on appearance, Ji et al. (2012) conducted a study on 84 adolescents with lupus and 80 healthy adolescents in China, where "appearance concern and depression" were assessed via the Children Depression Inventory (CDI) and the Self-Perception Profile for Children. The authors used correlation and multiple regression analyses to determine that "appearance concern" was related to the increased likelihood of depression.

A qualitative study conducted by Harry et al. (2019) examined the needs of patients with childhood-onset systemic lupus erythematosus by asking a simple question: "What are we missing?" In order to answer that question, the authors involved 31 patients whose ages range
from 12 to 24 years in a Midwestern Children's Hospital. Ten major themes were revealed from the established focus groups, which included: “knowledge deficits about childhood onset systemic lupus erythematosus, symptoms limiting daily function, specifically mood and cognition/learning, barriers and facilitators of adherence, and worry about the future.” There were additional themes that were unique to the adolescent/young adult participants, and they included symptoms that limited their daily functioning, such as pain, fatigue, self-care, impact on relationships, and communication with health providers.

As for the caregivers in this study, the themes that resulted from their input included the need for educational advocacy, consistent family schedules, and a sense of typicality or normalcy for their child (Harry et al., 2019). The American study conducted by Harry et al. (2019) and the Australian study conducted by Tunnicliffe (2016) demonstrated common themes despite the geographical differences. The authors specifically describe how frequent absences or even inadequate grades can have an "enormous impact on a child’s psychological development and quality of life” (LFA, 2019).

**Psychological and Socioemotional Factors in Lupus**

Although psychometric information, structured interviews, and clinical observations may offer professional insight into the level of functioning within pediatric lupus patients, examining patients with lupus through a contextual lens remain important. Stress, in general, has been recognized as contributing to flare-ups of the illness (LFA, 2019). Stress can also impair immune activity and produce increased inflammation and cytokine release (Feldman et al., 2018). For example, a longitudinal study conducted by Feldman et al. (2018) found that women and children who were abused during childhood had an increased risk of developing systemic lupus
erythematous. That longitudinal study correlates with previous findings regarding stress and lupus (Feldman et al., 2018).

There are a limited number of studies involving pediatric psychoneuroimmunology. Those studies that have been conducted demonstrate parallels to studies on psychoneuroimmunology in adults. Different types of stressors with differing timeframes of stress appear to produce different effects on the immune system (Herbert & Cohen, 1993). Stress has been shown to cause dysregulation in the immune systems of children with various chronic illnesses, such as lupus and asthma (Nassau, Tien, & Fritz, 2008). Miller and Cohen (2001, p.47) have found “modest evidence” that psychological interventions can alter immunity. Studies have even shown that children can learn self-regulation strategies that can positively impact the immune system, even some activity which were thought to be under autonomic control (Gertz & Culbert, 2009).

The psychoneuroimmunology behind this complex illness is important to understand as the association of school and lupus are linked when considering pediatric patients. Because of the legal mandate of school attendance, pediatric patients must comply with educational requirements despite their treatments. School is often viewed as a highly stressful environment, even for healthy students. Preidt (2019) found that stress and negative childhood experiences contribute to active lupus disease progression. That finding indicates a need for increased attention to the psychological well-being of all lupus patients, regardless of age or ethnicity.

The United Kingdom developed the "Educational Needs Assessment Tool," and a Dutch version was adapted from that measure (Zirkee et al., 2014). They used the "Educational Needs Assessment Tool" (ENAT) to objectively assess the educational needs of students with rheumatological conditions. Their sample of 244 students with lupus contributed to the discovery...
of patients' "substantial educational needs". The various domains that were found to be statistically significant included "self-help measures," "disease process," and "feelings." This practical discovery is applicable to the present study in justifying the need for further investigation of pediatric patients and their perceptions of school experiences (Zirkee, 2014). For pediatric patients, school can be a key element in their quality-of-life functioning.

A study focusing on quality-of-life issues among adolescents was conducted by Tunnicliffe et al. (2015) in five Australian hospitals from 2013 to 2014. This qualitative study utilized focus groups and interviews for thematic analysis. Five themes were identified by the researchers based on the participants’ responses. The title is representative of the underlying challenges which relates to the themes of the study: "Lupus Means Sacrifices." The themes which emerged from the patients' responses included (Tunnicliffe et al., 2015):

- "Marring Identity": Sense of isolation and misrepresentation of the self; Self-conscious beyond what is typical for adolescents
- "Restricting major life decisions": Limited career options; Possible risks regarding parenthood
- "Multifaceted confusion and uncertainty": Delay of diagnosis; Uncertainty regarding symptoms; Ambiguity regarding prognosis; Longing for remission
- "Resentment of long-term treatment": Discontent with long-term medication use; Irritation about medications’ side effects
- "Gaining resilience and coping strategies": Dependence on loved ones for support; Development of trust in the treating physicians; Learning ways to cope with the presenting challenges of the disease
The significance of this study lies in the fact that the responses of this population of late adolescent and early young adult patients with lupus are quite similar to full-grown adults with lupus. Similar themes were identified. Because of those issues, pediatric patients with lupus reported to have a lower quality of life than same-aged students without lupus (Tunnicliffe et al., 2015).

Ji et al. (2012) conducted a study on 84 adolescents who have SLE and 80 healthy adolescents in China, and "appearance concern and depression" were assessed via the Children Depression Inventory (CDI) and the Self-Perception Profile for Children. The authors used correlation and multiple regression analyses, and found that both factors contributed significantly to the increased likelihood of depression.

Lupus can also prompt feelings of anxiety and depression due to the constant uncertainty and unpredictability of the illness. Even those in remission may be fearful about flare-ups, which can occur at any time. Anxiety was found to be "a vulnerability factor" for depression (Lember, 2015). Zhang et al. (2017) conducted a systematic review and meta-analysis, and their conclusion was that the symptoms of anxiety and depression are so high in patients with lupus that they recommend routine psychological screenings for patients with lupus.

A cross-sectional study of young patients with lupus and healthy children resulted in a statistically significant difference in level of suicidal ideation (Knight et al., 2014). The results indicated that 14% of youth with lupus had suicidal ideation, whereas only 4% of the healthy participants had such thoughts. Studies such as these raise questions as to whether the rheumatologist, the school counselor, school psychologist, or others should regularly check on the adolescent patients’ ability to emotionally cope with all of their medical challenges.
Neuropsychiatric Lupus

According to Brunner and Klein-Gitelman (2009), neuropsychiatric lupus (NP-SLE) is “arguably the least understood manifestation of SLE” and they describe how NP-SLE presents through a very wide range of clinical presentations. These presentations can range from central nervous system disorders to cognitive dysfunction to peripheral nervous system disorders. According to Brunner and Klein-Gitelman (2009), 95% of pediatric patients manifest at least one symptom of NP-SLE.

The most common NP-SLE symptoms include headache and neuro-cognitive dysfunction. Manifestation of the symptoms may exhibit through impairment of attention, reasoning, sequencing, visual-spatial processing, recall, language, and psychomotor speed. Yu et al. (2007) conducted a 20-year longitudinal study that examined the neuropsychiatric manifestations among participants (n=185). They found that the most frequent types of neuropsychiatric manifestations include seizure disorder (84.4%), ischemic stroke (28.1%), and psychosis (21.9%) in pediatric systemic lupus erythematosus (Yu et al., 2007).

The American College of Rheumatology has recognized 19 specific neuropsychiatric syndromes that are linked with systemic lupus erythematosus. However, the established diagnostic criteria (based on the 1982 American College of Rheumatology), recognizes only two of them, and they happen to be neuropsychiatric in nature. They include psychosis and seizures (Popescu & Kao, 2011). Because of their specific inclusion in the diagnostic criteria and because of their possible impact on a pediatric patient’s neurological development, neuropsychiatric functioning is considered to be very important due to its developmental implications for learning. Children may present with some form of neuropsychiatric problems within the first few years of diagnosis (Toruner, 2017).
Neuropsychiatric lupus (NP-SLE) was described by Popescu and Kao (2011) as being "the least understood, but perhaps the most prevalent manifestation of lupus." They reported that it affects 22% to 95% of children, and these numbers are higher than adults. These researchers estimated that approximately 80% of adults with lupus present with NP-SLE syndromes involving the central nervous system and that approximately 95% of pediatric patients manifest at least one symptom of NP-SLE.

NP-SLE often develops early on during the disease progression, and about one-fourth of patients manifest symptoms within 30 days of the initial diagnosis. The severity of the symptoms can range from "mild impairment to severe dementia". Neuropsychiatric complications occur more frequently among children than among adults, which hold great implications for their learning process and their education. Neuropsychiatric lupus is also associated with increased mortality among patients.

According to Brunner and Klein-Gitelman (2009), NP-SLE is associated with a complex range of symptoms. This condition may present through symptoms such as cognitive dysfunction, seizures, psychosis, depressive disorders, and headaches. The most common NP-SLE symptoms are headaches and neurocognitive dysfunction (Brunner and Klein-Gitelman, 2009).

As for the etiology of NP-SLE in pediatric patients, the route of the disease activity is unknown at this time. Neurological complications for pediatric lupus patients often lead to an increased chance of morbidity and poor long-term consequences. One possible explanation involves the multi-faceted nature of neurocognitive dysfunction, which can involve the medical aspects of autoimmunity, such as auto-antibody production, microangiopathy, intrathecal production of cytokines which promote inflammation, and even atherosclerosis. Although
elevated cerebrospinal fluid levels of pro-inflammatory cytokines have been documented, the manner in which these cytokines impact the brain remains unknown.

The definitions for these syndromes were classified into two broad categories by the American College of Rheumatology in 1999: central nervous system and peripheral nervous system. The NP-SLE disorder relating to the central nervous system include, but are not limited to cognitive disorders, seizure disorders, psychiatric disorders, and headaches. NP-SLE relating to the peripheral nervous system include, but are not limited to cranial neuropathy, sensorineural hearing loss, and myasthenia gravis (Muscal & Brey, 2010). These disorders may explain why the prognoses of patients with NP-SLE often is negative due to cumulative neural/physical damage.

Besides psychosis and seizures, other central nervous system events may include headaches, cognitive dysfunction, mood disorder, anxiety disorder, acute confusional state, and aseptic meningitis (Popescu & Kao, 2011). For patients who experience such manifestations of central nervous system involvement, the treatment plan typically is to use high-dose glucocorticoids, intravenous cyclophosphamide pulse therapy, along with minimal use of corticosteroids, although there is a lack of consistency in the approach to managing central nervous system lupus. Having good differential diagnosis skills is crucial to treating NP-SLE, however, those symptoms often resemble classic mental illness and may be mistaken for psychological issues (Magro-Checa et al.).

Although neuropsychiatric involvement is common among patients with systemic lupus erythematosus, less than one-third of these events have been directly linked to it. Magnetic Resonance Imaging (MRI) tests are used to assist with the diagnostic evaluation, and blood tests can also reveal the extent of an inflammatory state. There is current research to better assist with
the biomarkers and pathologic mechanisms that can better provide evidence of the lupus-induced neuropsychiatric activity.

For example, Unterman et al. (2011) found that neuropsychiatric syndromes were evident in more than half of adult patients in their sample. The manifestations that were most commonly exhibited were headache, mood disorders, and cognitive issues. Significant differences were found for prevalence rates, which ranged from 12% to 95%. This finding may be due to the various screening methods, the baseline population, and the severity of the illness (Unterman et al., 2011).

Another concern/side effect of treatment is steroid psychosis. Steroid-induced psychosis can mimic NP-SLE, which is why the process of finding the correct differential diagnosis can be challenging. Stuart et al. (2005) reported that steroid-induced psychosis occurs in approximately 5 to 6% of adult patients who take that medication. The approximate figure for psychiatric issues range from 25% to 60% of pediatric patients who have systemic lupus erythematosus (Stuart et al., 2005).

Prior to modern-day research, it was thought that “steroid psychosis” was not evident in the pediatric population (Stuart et al., 2005). Eventually, Stuart et al. (2005) observed 16 cases of “steroid psychosis” in pediatric patients who were receiving “pulsed intravenous methylprednisolone,” which is commonly prescribed to pediatric patients. A review of the data showed that “adverse psychological side effects” manifested in children and adolescents a few days after the treatment was implemented (Stuart et al., 2005). This form of psychosis is usually induced by the consistent use of corticosteroids (Stuart et al., 2005). The manifestation is similar to typical psychosis.
Pediatric Neurocognitive and Psychoeducational Functioning

As discussed above, the presence of “adverse psychological side effects” covers a wide spectrum of symptoms that can manifest into serious levels of impairment in children. Before discussing pediatric patients’ psychoeducational issues, it is important to understand the neurological challenges that can directly impact the learning process of young patients with lupus in the school setting. Due to the cognitive impairment that is often associated with neuropsychiatric systemic lupus erythematosus (NPSLE), the practical manifestations of the illness can emerge as formally recognized learning disabilities or informally recognized learning challenges. Several recent studies have forged a growing link between autoimmunity and various brain disorders, which can affect the patient’s learning ability.

Cavasos-Garcia & Brey (2004, p.3) reported that “estimates of the prevalence of NPSLE have ranged from 14% to over 80%.” However, these issues may also manifest without signs of systemic disease activity (Muscal & Brey, 2010). Statistics regarding neurological manifestations have varied quite dramatically, due to the manner in which cognitive testing is conducted. When neuropsychiatric testing was completed on lupus patients, it consistently produced higher numbers of cognitive impairment compared to other types of assessments (Benedict et al., 2008). At this time, the reliability of neurobehavioral diagnoses remains vague due to the lack of reliable tests for detecting neurobehavioral syndromes that are specifically linked with lupus.

Brunner and Klein-Gitelman (2009) offered a possible explanation for the lower cognitive functioning among lupus patients by noting that the onset of lupus coincides with typical neural cognitive development in children. Neuroimaging studies show that adolescent brains do not mature until their twenties (Johnson et al., 2009). Because of the cognitive development that occurs during this time period, it is important to observe any changes in
memory and learning patterns. Consequently, it is possible that the neurocognitive issues are causal and/or related to lower test scores and low overall executive functioning and working memory. In addition to lower executive functioning, Williams et al. (2011) found significant impairment with psychomotor speed and fine motor skills.

Conti et al. (2012) reported that cognitive impairment can impact children and adolescents in almost every cognitive task, such as reading comprehension, academic performance, and intelligence. The neuronal dysfunction can impact processing skills which will impact the academic task at hand. These processing skills include visual memory and attention. Pediatric patients rarely undergo comprehensive psychoeducational evaluations so the extent of the cognitive limitations are rarely examined (Conti et al., 2012).

One aspect of a lupus patient’s learning process which may be impaired involves the cognitive challenges that often occurs with lupus (Benedict et al., 2008). This impairment is generally known as “lupus fog”. The specific areas which are associated with lupus fog include speed of information processing, working memory, visual/spatial memory, and memory, in general (Benedict et al., 2008). Memory can be impacted, either from the illness itself or as a result of pharmacological side effects. Patients with lupus often have difficulty with maintaining sustained attention to tasks, which medications likely exacerbate (Barraclough et al., 2019).

At this time, demographic factors do not appear to be predictive of neuropsychiatric issues in patients. There is no identifiable evidence of any consistent pattern relating to neuropsychiatric impairment. Comorbid psychiatric disorders with SLE are a valid possibility to explain the neuropsychiatric symptoms. Zelko (2012) reported that lupus can impair cognitive or psychiatric functioning during both childhood and adulthood. Neurocognitive dysfunction is elevated among patients with lupus in comparison to norms from the general population. This
issue has been found in matched cases comparing demographic factors. Iliades (2009) estimated that cognitive impairment occurs in child and adolescent patients at a rate of 59%.

Zelko (2012) conducted a study involving 40 pediatric patients with lupus and 40 same-gender best friend control participants. This matched design allowed for direct comparison of the 40 children and adolescents with a comparable control group. The participants were evaluated based on their demographics, academic functioning, behavioral and emotional functioning, and self-help functioning. In addition to having lower academic functioning, parents' ratings of school competence (as measured by the Child Behavior Checklist) was lower among patients with lupus then their best friends. The control group and the pediatric patients with lupus did not differ significantly on measures of cognitive, behavioral, emotional, or executive functioning. Pediatric patients were matched according to demographics, and those with SLE had significantly inferior academic outcomes, compared to comparable controls (Zelko, 2012).

The authors noted that school attendance and the side effects from serious treatments can impact the patients’ academic functioning. The authors concluded that pediatric patients “do in fact experience poorer academic outcomes than demographically-matched healthy peers, and that cSLE disease severity and treatment intensity are associated with school competence” (Zelko, 2012, p.1174).

Neurobehavioral disorders involve a large group of behavioral impairments that is associated with some type of brain injury or brain disease (Zasler, 2013). Symptoms of central nervous system (CNS) involvement may include loss of memory, concentration, attention, cognitive processing, and clear thinking. Due to the level of variability of the illness and variability of the medication(s) and dosages, which fluctuates according to periods of remission and flares, pediatric patients' cognitive functioning may not be as consistent as with other
students. Thus, educational plans may need to be updated according to changes in students’
medical status.

Boston Children's Hospital reported that up to 75% of patients with SLE experienced
neuropsychiatric symptoms. The reason for such high numbers remained a mystery until a
discovery which “has huge implications for a range of central nervous system diseases.” (Carroll,
2017). Carroll (2017) discovered a "surprising new link between inflammation and mental
illness" by using a mouse model of lupus to that connected inflammation to mental illness.
Neurobehavioral disorders involve a large group of behavioral impairments that is associated
with some type of brain injury or brain disease (Zasler, 2013).

Carroll and his team found that adequate interferon alpha was able to permeate the blood-
brain barrier and cause physical changes in the brain. Once it crossed the barrier, it was able to
launch microglia, which is the immunological defense cells of the central nervous system.
Microglia can be transformed into an attack mode on the neuronal synapse of the brain, which
may cause synapses to be lost in the frontal cortex. Microglia dysfunction has been observed in
other mental illnesses, such as schizophrenia. The research team attempted to reduce the loss of
synapses by using a drug that blocks the interferon Alpha receptor, commonly known as “anti-
ifnar.” It was discovered that the anti - ifnar offered some neuroprotective effects in mice with
lupus by preventing the loss of synapses. Thus, this study offers immunological insight into the
neuropsychiatric symptoms of CNS lupus (Carroll, 2017).

One hundred twenty-eight pediatric rheumatologists were surveyed regarding their
pediatric patients with CNS involvement. The results from the surveys indicated that 98% of
those pediatric rheumatologists preferred to have formal testing completed for pediatric patients
who show academic or cognitive issues (Brunner & Klein-Gitelman, 2009). However, there is
currently no standardized battery of neuropsychological tests which can be used as a valid and reliable measure of cognitive dysfunction in pediatric lupus patients, so diagnosing such a condition can be challenging among the pediatric population (Rubinstein, 2015). The Childhood Arthritis and Related Diseases Research Agenda (CARRA) Lupus Neuropsychiatric working group is currently working on establishing a valid battery of standardized measures (Rubenstein et al., 2015). Research is also being done to find non-invasive biomarkers which may indicate the level and specific type of neurological impairment(s).

**School and Systemic Lupus Erythematosus**

For pediatric patients, school is one of those issues that must be addressed due to its possible impact on the patients' health. During the 1950's, children with juvenile rheumatoid arthritis (JRA) were encouraged to be educated at home or be enrolled in special classes (Lovell et al., 1990). Nowadays, most pediatric patients with rheumatic conditions are able to thrive in general education classes with the support of a 504 Plan or with special education services. Barraclough et al. (2019) wrote that "any therapeutic interventions should be individually tailored" for patients with SLE.

Moorthy et al. (2010) reported that 83% of pediatric lupus patients in their study stated that they would have performed better in school had they been illness-free. That statistic demonstrates how students with lupus may not be able to achieve according to their academic potential due to their illness. Because lupus is a chronic condition, it will continue to impact the student into their college years and may determine if they can even attend college.

Education is an important factor in an adolescent's life, because those skills of childhood will gradually transfer into the occupational skills of adulthood. A successful educational career may open doors to future occupational options and opportunities. Occupational options are
limited otherwise due to the physical, cognitive, and financial constraints of chronic illness (Parks & Cooper, 2006). Morasso (2014) reported that students with chronic disabilities tend to have lower college graduation rates (46.9% vs. 51.7% in healthy peers) and lower persistence (staying in college) rates (55.3% vs. 59.2% in healthy peers). Childhood-onset lupus patients have been shown to have lower socioeconomic success than their healthy peers due to an inability to participate in higher education or the need to limit work hours for health reasons (Ravelli et al., 2005).

Tunnicliffe et al. (2015) stated that students with systemic lupus erythematosus have to restrict their goals and perspective of their future in terms of careers and activities. For example, lupus patients must take great care when choosing an occupation because certain substances may exacerbate the illness, such as silica, solvents, pesticides, and sunlight. (Parks & Cooper, 2006). The U.S. Department of Education (2005) reported that approximately half of students with disabilities who enrolled in post-secondary schools remained silent about their status of having disabilities by not informing their schools. Consequently, they were not provided with any type of service from disability offices on their campuses (Morasso, 2014).

The link between education and pediatric healthcare has not frequently intersected in the United States. Gavin (2015) reviewed recommendations on what teachers can do for students with lupus and provided a brief and general paragraph entitled "What Teachers Can Do". The main points in that brief paragraph warned educators that students may feel more "tired, sick, feverish, and achy than usual" (LFA, 2019). However, the only recommendations that were offered were to have the lupus patient rest or be excused from strenuous tasks and/or activities.

Now that many patients' life expectancy are lengthened due to improved treatments, it is even more important to examine quality-of-life issues, such as school, in light of lupus. The topic
of school is significant to most young patients' lives for both educational and medical reasons. In addition to being exposed to the curriculum, lupus patients are being exposed to countless bacteria and viruses on a daily basis, for a significant portion of their day. School then poses as a possible health hazard to immunosuppressed patients.

A study conducted by Zelko et al. (2012) revealed that children who have lupus demonstrated "inferior academic performance" than their healthy peers. It is not certain whether actual cognitive deficits account for the difference or not. For example, Frittoli (2016) reported that patients with lupus who experienced some form of cognitive dysfunction demonstrated a significant worsening of their mathematical skills. Frittoli's sample of 41 patients with lupus had a 41.46% rate of cognitive dysfunction. The conclusion of the study was that patients who exhibited concomitant cognitive dysfunction and lupus experienced worse mathematical skills than those without those issues. Because a pediatric patient's school attendance may be impacted by treatments and hospitalizations, it is not clear if the mathematical deficits would be restored or not during the remission phase of the illness.

Lupus patients may need to be absent more frequently than other students due to hospital stays for intravenous chemotherapy, medical tests, and/or medical appointments. By missing so much school, it can take a toll on patients' academic performance (Frittoli, 2016). Systemic lupus erythematosus involves extensive variability. The medical status of the patient fluctuates, so absences are often unpredictable. Missed days of school tend to result in extra work and extra stress for the student due to the necessity of completing current schoolwork, in addition to missed schoolwork. The significance of school also lies in the fact that students' "lessons" may also involve indirect lessons on socialization, communication, and conflict resolution.
Consequently, the school environment carries comprehensive benefits for the personal development of young patients, in terms of their academic and socioemotional functioning.

Studies on pediatric lupus patients indicate that they achieve worse academic outcomes than same-aged peers (Frittoli et al., 2016, Zelko, 2012). These results are not necessarily due to low intelligence or neurological damage. With the accumulation of missed assignments, students with lupus may experience extra stress and pressure, which can contribute to flare-ups of the illness. Disease progression and flare-ups can then take a cyclical turn and worsen patients’ academic performance. The chronic-relapsing course of the illness also interferes with a patient's stamina and educational progress.

No research addressing accommodations or effective strategic interventions for students with lupus has been conducted. School can be stressful for youngsters. Decreased stress and anxiety can lead to less autoimmune activity, and the possibility of remission (Levy, 2012). While this formula may not occur in such a clear-cut manner, the emphasis remains on the connection between the psyche and the immune system. That connection remains sensitive and active in the school environment, regardless of the patient's efforts or awareness.

Zelko (2012) conducted a study with 40 adolescent patients with lupus and 40 same-gender best friend control participants. The participants were evaluated based on academic functioning, behavioral functioning, emotional functioning, and executive functioning in daily life. In addition to having lower outcomes of academic functioning, parents’ ratings of school competence, as measured by the Child Behavior Checklist (CBCL), were lower among patients with lupus than their matched best friends. The mean scores were within the normal range, but there was a higher level of variability in the scores among the patients.
As for cognitive, behavioral, emotional functioning, and executive functioning, Zelko (2012) found that the lupus patients did not show significant differences in lupus patients' levels of performance. Standardized tests, such as the Child Behavior Checklist (CBCL), Behavior Rating Inventory of Executive Function (BRIEF), and Child Depression Inventory (CDI), were used to assess their functioning. The results of cognitive testing indicated the lupus group had a statistically significant weakness on the indices of Wechsler's "Working Memory" and "Processing Speed". They also had significantly higher scores on the CBCL's "Externalizing problems" and the BRIEF's "Behavior Regulation" indices and on the CDI measure of "Overall Depressive Symptoms". On the Wide Range Assessment of Memory Learning (WRAML)’s “Memory Screening Index”, the scores from the lupus group were higher than the control group.

According to Zelko (2012), the key factors which were associated with impaired educational performance were disease activity/severity and treatment intensity. The lupus group did not show other significant differences from the control group in terms of cognitive, emotional, behavioral, or executive functioning (Zelko, 2012). However, Dos Santos et al. (2010) found that a juvenile population of SLE patients had impaired verbal ability, which may impact all of those elements of daily functioning.

Although poor school performance can be a result of neuropsychiatric issues, Zelko did not find evidence that those issues are the catalyst for impaired academic functioning. This study did not examine attendance, but Zelko (2012) reported the possibility of attendance issues impacting the child's academic performance. It was specifically mentioned that disease activity and corticosteroid treatment are associated with poor school functioning. The authors of the study acknowledged that their definition of academic outcomes was based on a single measure and from a single informant, notably the parents.
Because the impact which lupus has on a patient's education has not been studied very much, some insight can be gained from comparable conditions such as juvenile idiopathic arthritis (JIA), which often affects those with lupus. Chomistek et al. (2017) reported that those with juvenile idiopathic arthritis reported that their school attendance and performance were only minimally impacted by their medical appointments and symptoms of their illness \((n=98)\). Instead, 42% of students with juvenile idiopathic arthritis reported that school was challenging due to the physical aspects of the illness (Chomistek, 2017).

Even though statistics are not available regarding the number of patients with lupus who have had special accommodations or services, there are studies that indicate such needs for the children of mothers with lupus. Lahita (1988) found that 45% (24/55) of sons of lupus-stricken mothers had a learning disability, such as dyslexia and that 10% of lupus patients' brothers had a learning disability. The study revealed that 12.5% of lupus patients often exhibited a learning disorder or dyslexia themselves. Lahita (1988) also reported that lupus patients were slightly more likely to be left-handed than the general population. The prevalence of autism in children of lupus patients is twice the number of the general population. All of these statistics may collectively explain why the number of children born by mothers with systemic lupus erythematosus require special education services in increasing numbers (Marder et al., 2014).

Zelko (2012) described the level of research in the area of education and lupus as being "surprisingly limited". He added that there is significant reason to be concerned about their academic outcomes due to the lack of occupational success on a long-term basis, a higher rate of mental illness as they enter adulthood, and even substance abuse. Quality of life studies are limited for minors with lupus.
Moorthy (2010) examined 41 pediatric patients with lupus using the "Simple Measure of Impact of Lupus Erythematosus in Youngsters", otherwise known as the SMILEY. Patients answered questions relating to school attendance and academic performance. According to the responses, patients reported having challenges related to their schoolwork. They also acknowledged their memory issues, which make learning and the ability to focus difficult.

In general, the patients self-reported that they were sad about the impact that lupus had on their schoolwork and attendance in class. Eighty-three percent of participating patients felt that they would have done better in school had they not had the diagnosis of lupus. Their study also found that patients who had intravenous chemotherapy had more absences than those who only took oral medications. Intravenous chemotherapy usually requires an overnight stay in the hospital. Those who missed the most school days also had the most disease activity.

Social Skills and School

Pediatric patients who have lupus reported having a lower quality of life than the typical student. Tunnicliffe (2016) recruited twenty-six pediatric patients to participate in either a focus group or a semi-structured interview. Results indicated that reasons for the lower quality of life include concerns over physical health, self-esteem, and school. Because the study targeted adolescents, self-esteem is a factor in their self-perception, which may relate to changes in their appearance (Tunnicliffe, 2016). School and worry are linked due to expectations regarding their academic performance.

School is a common place for children to establish peer friendships. Consequently, being absent from school equates with being absent from friends and classmates. Children often learn social skills through interactions with their peers during the school-aged years (Levy &
With lupus patients, peer support is more challenging to obtain due to school absences, which can lead to feelings of loneliness and isolation.

Medical isolation is sometimes mandated by physicians due to the use of immunosuppressive medications such as chemotherapy. Isolation extends beyond just the medical sense, because peer isolation also impacts the patients’ psyche. Peer relationships may not be ideal due to the lack of consistency of interaction. One study noted that there is no information for any specific interventions which can help the pediatric patients forge increased friendships and involvement in social activities (Nabors et al., 2015). However, the use of social media has helped with patient socialization (Pollio & Sciolla, 2019). The feeling of connectedness may allow a smoother transition back into school. Al-Sheyab and colleagues stated that a “peer-led education and support group” would be beneficial for a pediatric patient's “health-related quality of life, self-efficacy to resist negative health behaviors, and knowledge of best practices for illness management” (Nabors et al., 2015).

Building self-esteem can help alleviate feelings of loneliness and depression. Research assessing the social needs of children with general chronic illness shows that peer support can benefit them in the school environment (Nabors et al., 2015). Nabors et al., (2015) also reported that classmates who are educated about the medical condition of the child who is ill are more likely to be sympathetic to his/her needs. Parents should collaborate with the school staff, such as the school nurse, on what would be developmentally appropriate for classmates to know in light of privacy laws (Nabors et al., 2015).

Nabors et al. (2015) stated that medical staff should consider the child’s quality of life during medical visits by asking about their functioning at school. The authors noted that this is an indirect way of checking on the child’s emotional and social functioning. Knowing that
information is a means of monitoring distress, which can help prevent a possible flare-up of the illness (Nabors et al, 2015). The Lupus Foundation of America also recommends good parent-teacher communication for adequate disease management (LFA, 2019).

Educational Accommodations

The present study strives to answer questions surrounding the topic of accommodations in the school setting. Adult patients with systemic lupus erythematosus make up approximately 20% of Americans with a work disability (Agarwal & Kumar, 2016). Because lupus affects the patient’s ability to work in a "profound" manner, concerns were raised by Agarwal and Kumar about the younger population with this illness.

In addition to the obvious physical burdens of lupus, the financial and psychological toll continues to impact patients for a lifetime (Agarwal & Kumar, 2016). According to 393 respondents to an online survey, the main challenges of maintaining a full-time job are the fluctuation of the disease cycle, physical fatigue, and feeling "invisible" (Booth et al., 2018). Every respondent reported that lupus had a “detrimental” effect on their ability to work, and 40.45% left their employment due to the illness. By understanding the impact this disease has on adults, parallels can be drawn for the pediatric population as special consideration is given to their future outcomes.

The terms "accommodation", "modification", and “intervention” have been widely used in various contexts, which may encompass both educational and occupational realms. However, only an accommodation can be present on both 504 Plans and Individualized Education Plans (IEP’s). Accommodations can be legally carried from childhood into adulthood. A literature review conducted by Harrison et al. (2013) systematically produced the best definitions for all three terms based on their established criteria for the terminology. Accommodations differ from
modifications and interventions, because the curricular expectations remain the same as other students. Their distinct definitions are as follows (Harrison et al., 2013, p. 556):

Accommodations: "Changes in practices that hold a student to the same standard as students without disabilities (i.e. grade-level academic content standard) but provide a differential boost (i.e. more benefit to those with a disability than those without) to mediate the impact of the disability on access to the general education curriculum (i.e. level the playing field)"

Modifications: "Changes to practices in schools that alter, lower, or reduce expectations to compensate for a disability"
Interventions: "Changes made through a systematic process to develop or improve knowledge, skills, behaviors, cognitions, or emotions"

The University of Kansas offered an organized approach to defining "accommodations" by outlining four classifications of accommodations. The first category is entitled "Presentation Accommodations." This type of accommodation allows students to understand material without the need to visually decode it by using standard print. The second category is called "Response Accommodations," and this allows students to complete work and turn it in using an alternative format or device. "Timing/Scheduling Accommodations" allow changes involving time when dealing with due dates or the length of time required to complete projects, tests, and assignments. The final category is "Setting Accommodations", which involves the setting where the instruction or testing will occur.

Although legal mandates have been established to address workers with disabilities, it is unclear if lupus patients know they can have practical accommodations. Numerous lupus foundations and agencies recommend that pediatric patients request for accommodations to be applied into their educational program. However, statistics regarding their actual implementation are unavailable. The level of treatment fidelity by the teachers who are supposed to provide such
accommodations are also presently unknown. At minimum, the present study seeks to gather data on patients who are able to access some form of support for their education.

Because school can be stressful and having stress can trigger more autoimmune activity, it is important to alleviate or ease any stressors at school for the sake of improving the pediatric patient's quality of life. The decreased stress may even prolong their life. Improving the patient's school experience can also facilitate feelings of competency and lower anxiety and depressive symptoms. The interwoven effects of psychoneuroimmunology may then facilitate resilience via the mind and the body.

Providing educational accommodations for students with medical illnesses is complex due to the limitations of medical privacy (HIPAA). School staff members are required to abide by this federal law, and parents may offer medical information for safety reasons. Cunningham and Wodrich (2006) reported that detailed and relevant educational accommodations, which pertains to a child's illness, is associated with the amount of known medical information by the teacher. Consequently, increased details regarding the child's educational and medical needs often resulted in more disease-centered accommodations.

Chapter Summary

The results of this literature review indicates there is value and a great need for studying the topic of educational accommodations for students with systemic lupus erythematosus. This illness is marked by severe fatigue, a “butterfly rash”, photosensitivity, inflammation, and organ involvement. These symptoms can interfere with a young patient’s performance in the classroom. This life-threatening autoimmune illness can have a potentially deep impact on a patient’s basic functioning in daily living. Due to the spectrum nature of the illness and the variability of organ involvement, the prognoses of students will vary. Statistics show that lupus is
generally more severe and more deadly among pediatric patients than among adult patients. The majority of pediatric patients will survive, but struggle with ongoing symptoms. Because of that fact, extra support may be necessary in the school environment, which is why educational accommodations are a key means of providing that support.

   It is important to differentiate educational accommodations from other supportive strategies such as modifications and interventions. Educational accommodations hold students to the same curricular standards as other students. However, they provide “a differential boost…to mediate the impact of the disability on access to the general education curriculum” (Harrison et al., 2013, p.556). Because lupus symptoms often do not manifest in an obvious manner, questions remain as to whether students with lupus are given appropriate accommodations, which may ease their autoimmune symptoms and facilitate their learning.
Chapter Three: Methodology

Overview of Survey Administration to Minors

Surveys are a very useful tool for gathering information due to the ease of extracting first-hand, or primary, information from a participant. The medical field has increased the use of surveys as a data-collection tool for research in recent years (Colbert et al., 2013). Because of this, surveys have come to be "one of the most frequently employed study designs in healthcare epidemiology research" (Safdar et al., 2016). This methodology chapter's sequence will involve an examination of the constructed survey, the basis and reasoning for the chosen survey format, the practical details of data collection, and the summary of the participants in terms of each demographic variable.

According to DeFranzo (2012), there are many advantages to using surveys. For example, surveys are not as costly as other means of research. The possibility of capturing detailed information from a large population is also appealing to researchers. The variability and flexibility of the survey design allows it to be adaptable to the chosen research questions.

The ease and flexibility of surveys are made possible due to the beneficial use of technology (DeFranzo, 2012). Incorporating technological advances may benefit survey methodology. The most frequently utilized form of survey research in healthcare epidemiology is the online survey (Safdar et al., 2017). Computer software allows surveys to be disseminated globally and they can be statistically analyzed very quickly. Computers also allow a greater sense of anonymity for participants. Because surveys are theoretically easy to implement, it can be deceptive as to the amount of detail and time that is required in order to properly carry out the data collection.
In addition to having advantages, the use of surveys may hold some disadvantages in the research process. A few notable ones include the possibility of a low response rate, resulting in a small sample size (Safdar et al., 2016). The response rate is of great concern due to the goal of getting an accurate representation of the target population. A low response rate may lead to nonresponse bias, which must be considered when statistical calculations are conducted (Sadfar et al., 2016).

Concerns may also emerge if the target population does not have strong literacy skills. Good reading comprehension is vital for accurate survey completion, because it is crucial for the survey to correctly reflect the participant’s views. The target population may possibly be inattentive or uncooperative with the survey instructions (Safdar et al., 2016). As for survey responses from participants, their given responses may not be probed afterward for additional detail.

The use of surveys with adolescents holds special points to consider. Some may question if adolescents are capable of giving accurate self-report answers. A study by Fan et al. (2006) classified the inaccurate responses of adolescent falsifiers as falling into two distinct categories. They include “inaccurate responders” and “jokesters.” The “inaccurate responders” provide wrong answers due to the participant’s carelessness or confusion (Fan et al., 2006). The “jokesters” include those who intentionally provide false answers (Fan et al., 2006). The researchers reported that while the falsifying effect may not significantly impact research findings with large sample sizes, it remains a challenge for statistical accuracy to be established in the study.

There are also concerns as to whether adolescents are reliable enough to accurately self-report about their mood and mental status. Since concerns are already raised for those without
disabilities, concerns of accurate self-reporting are even higher among those with cognitive disabilities. This is definitely a concern among lupus patients due to the neuropsychiatric involvement that some pediatric patients may experience.

Nolan (2016) describes the seeking of health information in surveys as an example of self-reported health. It is a convenient manner of getting information due to the multiple dimensions and layers of health which can be accessed (Kuhn, Rahman, and Menken, 2006). Several decades ago, self-reported health was optimistically viewed as being a valid and reliable tool for research. As time passed on, researchers have discovered various conceptual and methodological challenges in studies involving youths and self-reported health. Adults’ self-reporting patterns have been studied for numerous years, and its study among adolescents has become more frequent and more detailed than in previous years. Numerous studies have tried to determine whether young children have the ability to assess their own health status (Riley, 2004). Age and maturity have been factors in the ability to participate in studies involving such skills (Riley, 2004).

Research involving self-reported surveys often accept proxy reports when the primary participant is unavailable or somehow impacted in terms of age or disability. The conclusion offered by Nolan (2016) stated that evidence for the use of both proxy and self-reports are valuable. The authors found that proxy reports were slightly more robustly associated with the amount of health information. Consequently, the authors recommended that researchers should involve both proxy and self-report surveys in situations involving adolescent health information. It is important to remember that the proxy and self-reports are not interchangeable, but they can definitely complement one another and provide possible correlational evidence between the two reports (Nolan, 2016).
Nolan (2016) discovered in their study involving adolescent self-reporting that all physical health indicators show an increased chance of being rated worse than the parent’s ratings. The only exception to this pattern occurs during puberty. It was specifically found that adolescent patients who have a long-term condition consistently produced “significantly higher odds of rating worse” on the health-related survey (Nolan, 2016). The statistic which they mentioned was that the pattern of “having a long-term health problem is associated with four times the odds” compared to their comparable peers (Nolan, 2016). Gender differences emerged as well with the parents of female adolescents less likely to state that their daughters have worse health than their peers. This result was not found among male adolescents.

In a study conducted by Arciuli et al. (2019), school satisfaction was examined through the interacting factors of gender and disability. The study included a sample size of 3,830 adolescents. Their results revealed that girls with disabilities “reported the lowest school satisfaction” and the strongest mediating variable appears to be the “perceived lack of teacher support” (Arciuli et al., 2019). Consequently, patients who have lupus are at high risk of having low “school satisfaction” since lupus tends to impact females. Extra attention should be directed to such students for the sake of disability care and their educational needs.

Jones et al. (2013) organized medical surveys/questionnaires into three categories. These three categories include epidemiological surveys, surveys regarding attitudes toward a particular intervention or service, and questionnaires tapping into the level of knowledge about a specific issue or topic. Healthcare surveys are unique due to the potential benefits it may generate for both healthcare providers and patients (Aday, 2006).

According to Lenhart (2013), efforts to conduct research on youth under the age of 18 years is limited due to the costs and complications which are involved. There are some
challenges that are unique to minors between the ages of 12 and 17 years old. For example, minors cannot consent to research without their parents’ approval. Consent varies by state but it stems from the opinion that adolescents are not yet capable of making good decisions that are in their best interest.

Contrasting opinion holds that the use of surveys among adolescents is appropriate, because their cognitive functioning is developed enough to understand concepts of negations and logic (de Leeuw, 2011). There has been debate over the developmental differentiation of adolescents from children (Santelli et al., 2003). These legal complexities must be addressed due to questions surrounding parental consent in research and the operational definition of a "minor". However, the limitations of research must be bound by ethical practice, in addition to legal compliance.

One example of such limitations involves statutes involving the Health Insurance Portability and Accountability Act (HIPAA) and minors. The Center for Disease Control (CDC) reported that only four states that have established specific laws relating specifically to adolescents, instead of using the terminology of "children" or "minors" (Santelli et al., 2003). Those states advocated that adolescents should be in a separate category due to the fact that this developmental stage is more autonomous and mature than individuals categorized as “children”.

Numerous studies are employing self-reporting measures in a wide variety of disciplines in order to gain information on children’s thoughts and feelings (Greco et al., 2016).

Proeschold-Bell categorizes test-takers into two general groups. She names these two groups of participants as “optimizers” and “satisficers” (Global Health Institute, 2018). The optimizers complete the survey with careful thought and dedicated motivation. The satisficers do not put forth an equal amount of effort into taking the survey. Proeschold-Bell reported that:
“You have to assume that everyone is going to be a satisficer, so you need to make all the steps as easy as possible.” That is why Proeschold-Bell recommends that the survey design consist of simple, concrete words (Global Health Institute, 2018). She also makes an interesting point that items which are placed at the end of a survey are prone to the “satisficers” influence, while optimizers appear to improve their accuracy as the survey progresses (Global Health Institute, 2018). The involvement of a neutral choice on the survey is dependent on which mindset will be taking the survey.

The surveys in the present study will elicit demographic information and input regarding the participant's current educational program and accommodations. The non-standardized surveys (see Appendix A) will be tailored toward patients who are in middle or high school, or parents of this pediatric population.

**Item Development and Content Validation**

**Item development.** Due to the passive approach to data collection in this study, one of the specific goals in this effort was to include eye-catching designs in order to attract interest and curiosity in the survey. By having such eye-catching designs in a hospital or clinic, patients and their parents would be more likely to look at the survey. Nolan (2016) reported that adolescents are more likely to take the survey if there is enough visual appeal.

Brevity is a key concern due to the possible joint pain which patients may experience during the writing process and/or the possibility of overloading patients with paperwork. Paperwork overload is possible for new patients, because they are usually asked to complete numerous medical forms during the initial appointment. If the survey appears long, it would be easy for them to ignore it. The survey must be brief and relevant enough to maintain prolonged
attention for survey completion. Nolan (2016) recommends the use of multiple-choice responses, because it facilitates brevity.

Because the surveys are anonymous, items requesting demographic information and health-related data were included. For example, there is an item requesting the participant to list his/her present medications. For example, chemotherapy was included as a factor within the analysis due to its common use among pediatric patients. That medicinal strategy is common during flare-ups of the illness (Castro-Santana, 2010).

The content for the surveys were extracted from various journal articles, with either an educational or medical context, which focused on SLE. In these articles, authors penned various accommodations which are recommended for individuals with this illness. The intent was to include pertinent, research-based accommodations, but the appearance of brevity remained an underlying factor during the survey construction.

Since there does not appear to be any studies relating to educational accommodations for lupus, accommodations of conditions which are considered to be medically related to the autoimmune family of illnesses were considered. Recommendations from a variety of medical publications and the implemented pilot test confirmed the relevance of the survey's list of accommodations for the school setting. The specific reasons to justify the inclusion of each accommodation on the survey are as follows:

1. Preferential seating: The student may sit in the front to boost alertness. The student may also sit in the back, for ease of exit to the bathroom or to the nurse's office.

2. Bathroom breaks as needed: Chemotherapy requires the patient to use the restroom more frequently in order to protect the patient from kidney complications.
3. Use of adaptive equipment for assignments: Arthritis is common in lupus, so writing may be painful and challenging.

4. Allow extra time between classes: Arthritis may affect mobility or the student may need to use the restroom.

5. Excuse from P.E. activities during active disease: Strenuous activity can aggravate the illness and lead to excessive fatigue.

6. Morning tardiness at school can be excused: Patients may need more time due to mobility issues and medication preparations.

7. Stretch as needed: Patients can relieve their arthritic joints through stretching.

8. Use of an elevator at school: Patients with severe mobility issues or severe fatigue may need this type of support because the use of stairs may be challenging.

9. Transportation to/from school: Patients with severe mobility issues may need the support if parents cannot transport the child.

10. Audio-record lectures/presentations: This would assist patients with frequent absences or those with arthritis.

11. Allow verbal answers/reports: This would help patients with arthritic hands.

12. Permission to wear hat in class: This would alleviate embarrassment over hair loss.

13. Can see school nurse as needed: Patients can receive medical assistance with any presenting symptoms at school. Patients may also rest in the nurse's office.

14. Extra time to complete assignments: This would help those with frequent absences or hospitalizations. Those with arthritis can have more time to write/type.

15. Allow access to sunscreen at school: Since sunlight must be avoided, the re-application of sunscreen is necessary.
16. Extra set of textbooks for use at home: Fatigue and arthritis can make carrying a heavy backpack a physical hardship.

17. Limit sun exposure: This will prevent a lupus flare-up.

18. Rest as needed: Severe fatigue is very common in patients with lupus.

19. Voice-typing software: This can help patients with arthritis.

20. Keep hand sanitizer on desk: Immunosuppressed patients must avoid germs and bacteria, which can complicate disease activity.

21. Sit in a comfortable style of desk: This can alleviate joint pain.

22. Provision of outlines/presentations: This is helpful for students with frequent absences or hospitalizations.

23. Shortened school day: This is intended for those with severe fatigue.

24. Permission to wear gloves as needed: Blood circulation in fingers is impacted in many patients with lupus (Raynaud's phenomenon).

An uncontrollable variable in the process of delivering established accommodations involves the consistency of its implementation. Thus, the survey included an item to estimate the teacher’s compliance with the patient’s accommodations. The level of compliance will help determine if the patient truly received the established support.

**Content validation.** The initial English survey was examined by three school psychologists, one teacher, one physician, and one professor. Feedback from the content reviewers included the following recommendations:

1. Use the term “student” instead of “patient.”

2. Include some type of notification to inform the participant that there is another side to the survey.
3. Add the term “guardian” instead of only using the term “parent.”

4. The title is deceptive, because it is not just a “school survey.”

5. Include “Other” in the gender options.

The bilingual version of the survey was constructed with the assistance of four fluent, bilingual individuals who work or used to work in the school setting. The Spanish-speaking translators included a veteran school secretary, a school psychologist, and two university professors. Consequently, their English and Spanish skills are well-versed in terminology that is appropriate to the school setting. Special attention was given to the range of Spanish fluency through the inclusion of translators with mild fluency to those with strong bilingual fluency. The intent was to make sure the surveys are understandable by all levels of Spanish-speaking individuals.

For the sake of efficiency, the English survey was translated into Spanish through an online interpretation program. After the resulting Spanish draft was produced, the bilingual individuals read the draft and made corrections as needed. After two translators made corrections to the survey, two other translators back-translated the translated draft to ensure accuracy and appropriateness. In addition to the surveys, assent and consent forms for the hospitals were also translated into Spanish.

The content validation process involved the distribution of the surveys to a small subset of the target population in order to verify the validity of the items. The pilot test consisted of patients with lupus and parents of children with lupus. Bilingual input was gained from a bilingual parent of an adolescent with lupus. Additional insight regarding the survey items were gained from an adult who had a personal diagnosis of lupus since her early childhood years.
Pilot Study

A pilot study was conducted at the rheumatology clinic of Children’s Hospital of Orange County. The surveys were completed by a convenience sample of five patients. The physician gave the paper survey to patients within the target age range. The pilot survey consisted of 25 items which were the same as the final copy, except for one item.

The patients were able to complete the survey correctly as intended. No feedback for improvement was given. One bilingual parent of a lupus patient and one adult lupus patient gave verbal feedback that the survey was understandable. The adult lupus patient suggested that physical education should be included in the survey, since that is physically strenuous for lupus patients. Because of her feedback, the accommodation of “Excuse from activities during active disease” was changed to “Excuse from P.E. activities during active disease.”

Because of the successful completion of the surveys by the patients and the parents, the survey was then translated into Spanish. The Spanish translation was read by a fluent Spanish speaker and a semi-fluent Spanish speaker. Both were able to understand the survey and its intent. The pilot study showed that the protocol for the study was feasible.

Procedure and Participants

Procedure

The final draft of the survey consisted of 25 items (See Appendix K). The survey, consent, and assent forms were approved by the Institutional Review Board of Chapman University, Children’s Hospital of Orange County, Cottage Hospital, and University of California Los Angeles' Mattel Hospital (Los Angeles, CA). The lead rheumatologists agreed to participate in the study. These key rheumatologists included Dr. Andrew Shulman (CHOC), Dr.
Miriam Parsa (Cottage), and Dr. Deborah McCurdy (UCLA). The population of focus are the pediatric rheumatology patients of the above-named physicians.

Surveys were constructed for pediatric rheumatology patients between 11 and 17 years of age. Surveys, consent forms, and assent forms were provided in Spanish and English. Surveys were placed near a locked box with a very thin slot for papers to be placed inside. It is similar to a mailbox. Signs were not allowed in a few of the hospitals, which was why there were no signs to alert patients of the surveys.

Once the surveys were completed by a patient or their parent/guardian, patients were supposed to fold the survey and insert them into the mailbox-like box with a lock. As patients and parents waited to see their physician, they could complete the survey during their wait. This passive method of recruitment is reliant on the potentially excessive boredom which patients may possibly experience during their wait to see the rheumatologist. The surveys were available in all three clinics for a period of approximately 5 months.

Due to the lack of surveys involved with this type of investigation, the present survey was designed based on general accommodations which lupus organizations and medical websites have recommended. Rankings were used instead of simple multiple-choice selections, so that more information can be gained regarding the differences between the choices. For example, having an accommodation chosen as the top choice by numerous patients shows the relationship between that top choice and other options. It is also helpful to see if there is a specific pattern in the ranking, such as intervention A always proceeding intervention D or intervention B always following intervention C. The surveys are limited to just English and Spanish translations.

The reason for providing sample accommodations for the patient to circle/underline is due to the possible physical and neuropsychiatric issues in patients with lupus, especially for
those who are taking high doses of steroids. By seeing some possibilities, it may help the patient
to recall their own accommodations more easily. As for content validation of the survey, the
survey was examined by three university professors and at least one rheumatologist.

Scoring simply involved counting the votes for each accommodation. The medications
which were listed was examined carefully to ensure their validity. For example, some
participants listed their vitamins in addition to their medications. The vitamins were not counted
toward the medication totals.

Participants

Participants in the present study were middle school or high school students who have
systemic lupus erythematosus. Their ages ranged from 11 to 18 years, with the mean age being
15.17 (SD=2.34). The participants’ grade levels ranged from 6th grade to 12th grade. The sample
consisted of 32 females, 3 males, and 1 identifying as “Other.”

Table 1

*Age Levels of the Participants*

<table>
<thead>
<tr>
<th>Age</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>12</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>14</td>
<td>8</td>
<td>20.5</td>
</tr>
<tr>
<td>15</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>16</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>17</td>
<td>6</td>
<td>15.4</td>
</tr>
<tr>
<td>18</td>
<td>8</td>
<td>20.5</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 2

*Grade Levels of the Participants*

<table>
<thead>
<tr>
<th>Grade</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>8</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>9</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>10</td>
<td>6</td>
<td>15.4</td>
</tr>
<tr>
<td>11</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>12</td>
<td>11</td>
<td>28.2</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 3

*Gender of the Participants*

<table>
<thead>
<tr>
<th>Gender</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>Females</td>
<td>32</td>
<td>82.1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>7.7</td>
</tr>
</tbody>
</table>

These students were patients in one of the three participating lupus clinics (Children’s Hospital of Orange County, Cottage, UCLA Mattel Hospital). The ethnic backgrounds of the participants were primarily from minority groups, namely Hispanic, African-American, and Asian backgrounds. The participant characteristics are representative of the typical lupus patient population. The high number of female and ethnic minority patients are representative of typical lupus patients.
Table 4

*Ethnicity of the Participants*

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>African-American</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>19</td>
<td>48.7</td>
</tr>
<tr>
<td>White</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Missing</td>
<td>10</td>
<td>25.6</td>
</tr>
</tbody>
</table>

All of the participating students were passing their classes, according to their grade point average (GPA). The mean grade point average for this sample is 3.60 (SD=0.58). This number appears to be rather high considering the various challenges which the students have in terms of disease activity, medication side effects, and possible school attendance issues.
Table 5

*Grade Point Averages of the Participants*

<table>
<thead>
<tr>
<th>Grade Point Average</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.00</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>2.90</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>3.00</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>3.20</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>3.30</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>3.50</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>3.70</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>3.80</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>3.92</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>3.99</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>4.00</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>4.40</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>4.50</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>4.70</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Missing</td>
<td>14</td>
<td>35.9</td>
</tr>
</tbody>
</table>

Since almost one-third of the patients were not taking corticosteroids, it is possible that many of the patients in the present sample are in the remission phase of the lupus cycle. Being in the remission phase equates with less severe symptoms of the illness. Many patients did not give their corticosteroid dosages, but the ones who did were taking low to moderate doses. Twenty-five of the participants were ingesting corticosteroids and five of them were undergoing chemotherapy.
Table 6

Participants' Medication Details

<table>
<thead>
<tr>
<th>Corticosteroid Intake</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25</td>
<td>64.1</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>28.2</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>7.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chemotherapy Intake</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>No</td>
<td>31</td>
<td>79.5</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>7.7</td>
</tr>
</tbody>
</table>

The mean number of total medications that were being ingested was 2.6 (SD=1.83). That means that their disease activity likely is under control enough to function adequately at school. The total number of medications also shows that most of the participants were doing well healthwise, since almost one-third of them were taking only one medication.

Table 7

Total Number of Medications Taken by Participants

<table>
<thead>
<tr>
<th>Total # of Medications</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>1</td>
<td>12</td>
<td>30.8</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>17.9</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td>10.3</td>
</tr>
</tbody>
</table>
The following table provides information on the family’s income:

Table 8

*Family Income of the Participants*

<table>
<thead>
<tr>
<th>Family Income</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$20,000</td>
<td>9</td>
<td>23.1</td>
</tr>
<tr>
<td>&lt;$40,000</td>
<td>11</td>
<td>28.2</td>
</tr>
<tr>
<td>&lt;$60,000</td>
<td>8</td>
<td>20.5</td>
</tr>
<tr>
<td>&lt;$80,000</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Above $80,000</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>12.8</td>
</tr>
</tbody>
</table>

The participants may also be parents/guardians of these students since the survey allows its completion by either the parent/guardian or the student. Assent and consent forms were provided for the patients and their parents/guardians to review prior to giving their informed consent.

**Chapter Summary**

The present study required unique medical and educational considerations for the different variables of the survey development process. The non-standardized survey consisted of four sections with a total of 25 items. The four sections included a demographic section, a school services inquiry, a school accommodations inquiry, and rankings of present and ideal accommodations. The demographics section included specific questions about the student's personal and medical background. The next section inquired about any educational support which the student may have been receiving. The accommodations inquiry required the student to identify all of the accommodations which were presently being provided to the student. The
concluding section asked the participant to choose the best three accommodations which were presentely being provided to him/her. The final step in that section involved ranking the top three ideal accommodations for students with SLE to have in order to earn a high school diploma.

The survey was then examined by a panel of four psychometric professionals, one medical professional, and two lupus-acquainted individuals to ensure adequate content validity. Four bilingual professionals were involved in producing a Spanish translation of the survey. A pilot study was conducted at Children's Hospital of Orange County.
Chapter 4: Results

The variables of presently given accommodations and ideal accommodations were examined and compared for similarities or differences. Any possible correlation between medications and grade point average were also examined. Descriptive statistics were used to examine formalized plans and programs. The small sample size of 39 limits the use of extensive statistical analysis due to its limited statistical power. There is a greater margin of error with a small sample size. Consequently, a few statistical analyses will be offered, but the main results cannot be tested for significance. Cell values involved very low numbers and there were numerous ties involving those low numbers. A descriptive analysis will be offered through a direct summary of the findings. The data were analyzed using a Pearson correlation coefficient and a Spearman's Rho correlation coefficient.

A Pearson correlation coefficient was specifically used to examine the correlation between participants’ grade point average and their total number of medications. The resulting statistic was -.333 (p = .104). Thus, there was a moderate, inverse relationship where higher number of medications ingested was associated with the lower grade point averages, although the result was not statistically significant.

Due to the categorical variables involved, a Spearman's Rho was conducted in order to examine the relationship between the students' present accommodations and ideal accommodations. The results revealed a moderate, statistically significance relationship between the second-place present accommodation and the second place ideal accommodation (r = .452, p = .035). There were no other significant correlations. Because there are no studies examining these variables, the results cannot be compared with past findings.
Table 9

*Spearman's Rho Correlation Coefficients*

<table>
<thead>
<tr>
<th></th>
<th>Ideal 1</th>
<th>Ideal 2</th>
<th>Ideal 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accom 1</strong></td>
<td>Correl. Coeff.</td>
<td>.256</td>
<td>.304</td>
</tr>
<tr>
<td>p Value</td>
<td>.216</td>
<td>.149</td>
<td>.063</td>
</tr>
<tr>
<td><strong>Accom 2</strong></td>
<td>Correl. Coeff.</td>
<td>.167</td>
<td>.452*</td>
</tr>
<tr>
<td>p Value</td>
<td>.447</td>
<td>.035</td>
<td>.867</td>
</tr>
<tr>
<td><strong>Accom 3</strong></td>
<td>Correl. Coeff.</td>
<td>-.226</td>
<td>-.290</td>
</tr>
<tr>
<td>p Value</td>
<td>.299</td>
<td>.191</td>
<td>.709</td>
</tr>
</tbody>
</table>

*p < .05, two-tailed

One-third of the students had 504 plans while slightly less than one quarter had Individualized Education Plans (IEP’s). Thus, most of the students in the present sample had some type of additional academic support in place at their schools.
Table 10

*Summary of Presently-Provided Services*

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>504 Plans</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>33.3</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>38.5</td>
</tr>
<tr>
<td>Don't Know</td>
<td>8</td>
<td>20.5</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td><strong>IEP’s</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>23.1</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>61.5</td>
</tr>
<tr>
<td>Don't Know</td>
<td>2</td>
<td>5.1</td>
</tr>
</tbody>
</table>

The total number of accommodations also shows that to be true. Only one student out of 32 who responded did not receive any accommodations.
Table 11

*Total Number of Formal and Informal Accommodations Provided to Participants*

<table>
<thead>
<tr>
<th>Total Accommodations</th>
<th>Number of Students</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>1</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>7</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>9</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>14</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>16</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>17</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>18</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Missing</td>
<td>7</td>
<td>17.9</td>
</tr>
</tbody>
</table>
An inquiry into teachers’ compliance rate with their students’ accommodations produced the following results. The responses were too few to draw any formal conclusions.

Table 12

*Teacher Compliance with Students’ Accommodations*

<table>
<thead>
<tr>
<th>Compliance Percentage</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>50%</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>70%</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>90%</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>100%</td>
<td>4</td>
<td>10.3</td>
</tr>
</tbody>
</table>

Based on the students’ survey responses, the accommodation that was consistently chosen most frequently was “Extra time to complete assignments.” It was the top choice for the most valuable accommodation which they were presently receiving for all three rankings (first choice,
second choice, and third choice). It was also the top choice for the ideal accommodation for a student with lupus (most ideal, second ideal, and third ideal choice).

Table 13

*Participants’ First Place Rankings of Present Accommodations*

<table>
<thead>
<tr>
<th>First Choice of Present Accommodations</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 (Bathroom breaks as needed)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>3 (Use of adaptive equipment for assignments)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>4 (Allow extra time between classes)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>5 (Excuse from P.E. activity during active disease)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>6 (Morning tardiness at school can be excused)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>8 (Use of an elevator at school)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>9 (Transportation to/from school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>13 (Can see school nurse as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>14 (Extra time to complete assignments)</td>
<td>8</td>
<td>20.5</td>
</tr>
<tr>
<td>16 (Extra set of textbooks for use at home)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>18 (Rest as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Missing</td>
<td>9</td>
<td>23.1</td>
</tr>
</tbody>
</table>
As for the rest of the accommodations which clustered at the top of the list of accommodations which they were receiving, the participants voted for “Bathroom breaks as needed”, “Excuse from P.E. activities during active disease”, “Can see school nurse as needed”, and “Limit sun exposure.” Those five accommodations, including “Extra time to complete assignments”, were voted as being most helpful out of the accommodations which they currently had.

On the list of ideal accommodations, the cluster of most frequently chosen accommodations after the top choice of “Extra time to complete assignments” included a wider variety of choices. They included “Excuse from P.E. activities during active disease”, “Morning tardiness at school can be excused”, “Bathroom breaks as needed”, “Extra set of textbooks for use at home”, “Rest as needed”, and “Shortened school day.” Two individuals wrote in accommodations of their own, which was having a “notetaker” in class. All of these
accommodation choices can benefit students with SLE who are suffering from either mild to severe disease activity.

Table 14

*Participants' First Place Rankings of Ideal Accommodations*

<table>
<thead>
<tr>
<th>First Choice of Ideal Accommodations</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 (Allow extra time between classes)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>5 (Excuse from P.E. activity during active disease)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>6 (Morning tardiness at school can be excused)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>8 (Use of an elevator at school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>9 (Transportation to/from school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>10 (Audio-record lectures/presentations)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>13 (Can see school nurse as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>14 (Extra time to complete assignments)</td>
<td>9</td>
<td>23.1</td>
</tr>
<tr>
<td>15 (Allow access to sunscreen at school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>16 (Extra set of textbooks for use at home)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>17 (Limit sun exposure)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>18 (Rest as needed)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>21 (Sit in a comfortable style of desk)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>25 (Other)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Missing</td>
<td>11</td>
<td>28.2</td>
</tr>
</tbody>
</table>
The participants clearly made their choice with “Extra time to complete assignments” being the most desired accommodation from their list of present accommodations and their list of ideal accommodations. This accommodation does not directly benefit their physical well-being, but instead benefits their academic functioning. Since the sample apparently consists of pediatric patients on the milder end of the autoimmune spectrum, it is logical for physical well-being to not be a top concern in their daily functioning. In order to maintain good grades, having the extra time to complete assignments would compensate for time lost to medical appointments and treatment.

Based on the presently-given accommodations, the top choices for second place resulted in a three-way tie. They included “Bathroom breaks as needed”, “Excuse from P.E. activity during active disease,” and “Extra time to complete assignments.” As for the third place choice,
“Extra time to complete assignments” took the lead, with seeing the school nurse being close behind it.

Table 15

*Participants' Second Place Rankings of Present Accommodations*

<table>
<thead>
<tr>
<th>Second Choice of Present Accommodations</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 (Bathroom breaks as needed)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>5 (Excuse from P.E. activity during active disease)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>7 (Stretch as needed)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>8 (Use of an elevator at school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>9 (Transportation to/from school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>11 (Allow verbal answers/reports)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>12 (Permission to wear hat in class)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>13 (Can see school nurse as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>14 (Extra time to complete assignments)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>15 (Allow access to sunscreen at school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>16 (Extra set of textbooks for use at home)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>17 (Limit sun exposure)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>18 (Rest as needed)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>22 (Provision of outlines/presentations)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>25 (Other)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Missing</td>
<td>12</td>
<td>30.8</td>
</tr>
</tbody>
</table>
Figure 4

Participants’ Rankings of Second Place Present Accommodations

![Bar chart showing distribution of second place rankings]

Table 16

Participants' Third Place Rankings of Present Accommodations

<table>
<thead>
<tr>
<th>Third Choice of Present Accommodations</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 (Bathroom breaks as needed)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>4 (Allow extra time between classes)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>5 (Excuse from P.E. activity during active disease)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>6 (Morning tardiness at school can be excused)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>13 (Can see school nurse as needed)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>14 (Extra time to complete assignments)</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>15 (Allow access to sunscreen at school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>16 (Extra set of textbooks for use at home)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>17 (Limit sun exposure)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>18 (Rest as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>20 (Keep hand sanitizer on desk)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>23 (Shortened school day)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Missing</td>
<td>12</td>
<td>30.8</td>
</tr>
</tbody>
</table>
Figure 5

Participants’ Third Place Rankings of Present Accommodations
Table 17

Participants' Second Place Rankings of Ideal Accommodations

<table>
<thead>
<tr>
<th>Second Choice of Ideal Accommodations</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 (Bathroom breaks as needed)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>4 (Allow extra time between classes)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>5 (Excuse from P.E. activity during active disease)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>6 (Morning tardiness at school can be excused)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>7 (Stretch as needed)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>9 (Transportation to/from school)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>12 (Permission to wear hat in class)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>14 (Extra time to complete assignments)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>16 (Extra set of textbooks for use at home)</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>17 (Limit sun exposure)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>18 (Rest as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>19 (Voice-typing software)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>21 (Sit in a comfortable style of desk)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>22 (Provision of outlines/presentations)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>23 (Shortened school day)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>25 (Other)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Missing</td>
<td>12</td>
<td>30.8</td>
</tr>
</tbody>
</table>
Figure 6

*Participants’ Second Place Rankings of Ideal Accommodations*

![Bar chart showing second place rankings of ideal accommodations.]

**Table 18**

*Participants’ Third Place Rankings of Ideal Accommodations*

<table>
<thead>
<tr>
<th>Third Choice of Ideal Accommodations</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Preferential Seating</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>2 (Bathroom breaks as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>4 (Allow extra time between classes)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>5 (Excuse from P.E. activity during active disease)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>6 (Morning tardiness at school can be excused)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>7 (Stretch as needed)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>11 (Allow verbal answers/reports)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>13 (Can see school nurse as needed)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>14 (Extra time to complete assignments)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>17 (Limit sun exposure)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>18 (Rest as needed)</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>23 (Shortened school day)</td>
<td>4</td>
<td>10.3</td>
</tr>
<tr>
<td>24 (Permission to wear gloves as needed)</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>25 (Other)</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Missing</td>
<td>12</td>
<td>30.8</td>
</tr>
</tbody>
</table>
Chapter Summary

The present findings demonstrate that most of the pediatric patients in this sample were receiving some type of accommodation from their schools, whether it be formal or informal support. The formal support consists of one-third of students having 504 plans and almost one-quarter having individualized education plans. The general demographics of the small sample appear to be representative of typical pediatric lupus patients, due to the predominance of the female gender and the predominance of ethnic minority groups in the sample. All students, except two, were able to achieve grade point averages above a 3.00.

An examination of the rankings revealed that one accommodation stood out from the rest. It was consistently voted within the top three accommodations on both the list of present accommodations and the list of ideal accommodations. That winning accommodation was “Extra time on accommodations.” The highest-ranking cluster of accommodations on the list of present
accommodations besides the top accommodation included “Bathroom breaks as needed” and “Excuse from P.E. activities” during active disease. The votes were more varied on the ideal list of accommodations.
Chapter 5: Discussion

The purpose of the present study was to examine the provision of educational accommodations to students who have systemic lupus erythematosus. Data were collected through a 25-item paper survey which were completed by 39 participants.

Overall, the grades of the participants appears to be rather high for a sample with health issues which may affect school attendance and academic performance. It is possible that their grades were good due to the implementation of appropriate accommodations. Another possible reason for the good grades involves adult accountability. In addition to parents asking about their academic performance, they also have a medical team (physicians, nurses, medical social workers) who are regularly inquiring about their school functioning.

A different perspective for the high grade point average points to the possibility that most of the participants were attending high school. High school students may be more inclined to have higher grades due to possible plans of applying to colleges and universities. High school students would be more motivated to perform at their best while middle school students lack such immediate pressure. The additional issue of maturity may be an underlying factor as well.

Research Question 1a: What are the educational accommodations that a participant is presently receiving?

Based on the 39 participants’ survey responses, every one of them had some type of formal or informal accommodation in place at their school, except for one student. Only one student out of the 39 participants did not receive any extra support. Approximately 56% of the students did not have formally established accommodations, while 44% had formally authorized accommodations through a 504 Plan or an IEP. Some students did not know whether or not they had a 504 plan or an IEP.
Research Question 1b: What are the student's favorite accommodations in rank order out of the presently-received accommodations? The participants were asked to rank their current accommodations (which were provided by their schools) according to their helpfulness toward earning a high school diploma.

When asked to rank their given accommodations according to their effectiveness for earning a high school diploma, the participants chose 1) Extra time to complete assignments 2) Bathroom breaks as needed 3) Excuse from P.E. activity during active disease. Those second and third choices were tied at four votes each, which fell distantly behind the leader with eight votes.

Research Question 2: What is the student's preferred or ideal accommodations in rank order in terms of helpfulness toward earning a high school diploma?

When asked to choose the ideal accommodations for a student with SLE, the participants picked 1) Extra time to complete assignments, 2) Morning tardiness at school can be excused, 3) Excuse from P.E. activity during active disease. Those second and third choices were tied at three votes and fell distantly behind the first choice with nine votes.

Research Question 3: Is there any correlation between participants' grade point average and their total number of medications?

A Pearson correlation coefficient was calculated to see if there was any correlation between participants’ grade point average and their total number of medications. The resulting statistic was -.333, \( p = .104 \). Thus, this small sample does not appear to demonstrate a statistically significant relationship between the variables of grade point average and total number of medications. A larger sample size, with added statistical power, may possibly lead to a stronger relationship.
Research Question 4: What is the percentage of students who currently have a 504 Plan or an Individualized Education Program (IEP) in place?

In this sample of 39 participants, nine of them had IEP’s and 13 had 504 Plans. In terms of percentages, 23.1% of the sample had IEP’s and 33.3% of the sample had 504 plans.

Research Question 5: How similar or dissimilar are the rank-ordered lists of given accommodations and the ideal accommodations?

It appears that both lists of given accommodations and ideal accommodations share the most frequently chosen accommodation, which is "Extra time to complete assignments". There was more variation in responses on the list of ideal accommodations. There were also more choices that may be difficult to obtain from a school, such as a "shortened school day", "extra set of textbooks for use at home", and having a "notetaker."

Summary of the Findings

Overall, the results indicated that the majority of students who participated in the present study received some type of accommodation to alleviate the challenges involved with systemic lupus erythematosus. When the participating students were asked to rank their favorite three given accommodations that would help to achieve a high school diploma, the highest ranking accommodations included "Extra time to complete assignments, "Bathroom breaks as needed", and "Excuse from P.E. activity during active disease." When the participating students were asked to give three ideal accommodations that would help to achieve a high school diploma, their highest chosen accommodations included "Extra time to complete assignments," "Morning tardiness at school can be excused," and "Excuse from P.E. activity during active disease."

Based on this small sample, almost one-quarter of the students had an IEP, and one third of the students had a 504 Plan.
**Study Strengths**

The opening strength of the present study lies in the fact that this is the only examination that has been conducted of the specific educational needs of secondary students with systemic lupus erythematosus, according to the available literature. A key strength of the study involved the participation of three hospitals. Having three hospitals increased the likelihood of a reasonable sample size. In addition, it increased the likelihood of achieving a diverse range of illness severity and diversity in ethnic and socioeconomic backgrounds. The wide spectrum of illness severity can be observed through the medications which were listed. Some students were prescribed small maintenance dosages of medication, while others were administered several serious medications, such as chemotherapy. The demographic data results showed that a diverse representation of individuals was achieved. Furthermore, it mirrored previous research data on how SLE affects minorities at a significantly higher rate than Caucasians. It was also advantageous to have a Spanish translation of the survey, considering that many of the survey participants are ethnically Hispanic.

The content of the survey appears to be a strength, because each of the accommodations on the survey was checked at least once in some manner. This demonstrates the validity of the content, since the students chose the accommodation, either as a wish or as a present provision. Consequently, the listed accommodations accurately reflected their needs in the educational environment.

**Study Limitations**

The primary limitation in the present study is the small sample size which resulted from the passive approach to data collection. The data collection period occurred over a 5-month
timeframe, but the response rate remained low at all three hospitals. One of the reasons for this phenomenon involved the age of the target population.

At the largest hospital, the lupus patients were more likely to be within the college-aged range rather than in the secondary school range. It just so happened that the majority of patients at that hospital were young adults who were attending college instead of high school. Thus, they could not take the survey since the target population was middle or high school students.

The issue of age relates to the statistic regarding the length of time it takes to diagnose a new patient with lupus. The median age for the symptoms of lupus to emerge is between 14 to 15 years old. As mentioned in the literature review, the timeframe from noticeable symptoms to an actual diagnosis is around 6 months. By combining the statistics which were cited, the average pediatric lupus diagnosis (14.6 years) added with the timeframe toward an actual diagnosis would equal approximately 15 years of age. The diagnosis of younger children is more challenging due to the cognitive and verbal skills which are needed in order to express discomfort or problematic physical functioning. Because of that estimated statistic, the study would probably have had more high school students than middle school students. That statistic decreases the likelihood of participation by middle school students, which would further limit the sample size.

Age is a factor affecting the outcome of this study for an additional reason. Due to the present digital age of technology, it is possible that the rate of participation could have been improved by using online surveys instead of paper surveys. Some may argue that the new generation of adolescents in middle and high school would prefer online surveys over paper surveys. Research-based evidence has not been solidly established yet regarding this issue of preferences in survey participation.
A major factor to consider involves the challenge of recruiting minority participants for the study since SLE often affects minority communities. Minorities have long been underrepresented in research (Diaz, 2012). George et al. (2014) reported that the level of mistrust by minorities manifests differently so there must be culture-specific strategies to reach each group. The word “research” can evoke feelings of fear as visual images of laboratories and medical procedures come to mind. They may not be familiar with the possibility of other types of research.

Language is the other barrier to participating in research. Even though the present study has a Spanish version of the survey, SLE affects many other cultures. For example, systemic lupus erythematosus frequently affects Asian countries. Yet, there were no bilingual versions of the survey for those bilingual communities. These significant barriers of language and unfamiliarity may impede research by limiting the sample size. All three hospitals in this study have a significant variety of ethnic backgrounds, but the largest minority group among the three hospitals are bilingual in Spanish.

The lack of diversity in the small sample can be observed through the high grade point averages and mild form of SLE. The majority of the participants had grade point averages above a 3.00. The majority of participants likely also had mild cases of lupus, based on the medications and dosages which they revealed in their surveys. So, the typical participant appears to be a good student who is only experiencing mild symptoms of the illness. The small sample of these types of participants further limits the generalizability of this study’s findings.

**Implications for Practice and Training**

This study provides evidence that it is possible for students with lupus to achieve academically in a manner that is comparable to their peers. However, they display enough needs
and limitations to qualify for IEP's and 504 Plans. Teachers were sympathetic enough to provide informal accommodations to students if they did not have a formally established set of accommodations. It is possible that the patients' high grade point averages may be the result of the implementation of the accommodations. If that truly is the case, then this study would provide some evidence of the beneficial effects of providing accommodations to students with lupus. It is important to remember the possibility that this self-selected sample may have a confounding variable involving an association of high achievement and willingness to take the survey. The high achievement may further relate to being high school-aged.

Participants in the present study chose their top three ideal accommodations as extra time on assignments, being excused from P.E. activities during active disease, and forgiveness of morning tardiness. Having extra time on the assignments would allow the students to use some time for rest and medical appointments and the additional time can be dedicated to their assignments. The accommodation of being excused from P.E. activities would shield students from sun exposure and strenuous activities. Finally, the freedom to be tardy allows students adequate time to take medications and put on sunscreen. While the top choice has an indirect benefit to pediatric patients, the second and third choice are more closely linked with illness. These accommodations do not demand much time or effort from teachers, which makes them more likely to be implemented without complaint.

Since the list of ideal accommodations and the list of presently given accommodations are almost identical, it shows that the participants are able to get what they want from their schools. What they currently have is what they would like to have. This may be due to the participants’ self-advocacy for these accommodations and/or the school’s sensitivity to the
participants’ needs. Either way, self-advocacy for each student remains important in order to get all of the ideal accommodations established through formal documentation.

Even though a direct causal relationship between certain school accommodations and stable health cannot be established, the peace of mind which the students and their parents can have in knowing they are supported at school is helpful for their psychological well-being, which can indirectly boost their physical well-being. Since most of the accommodations which the patients were receiving were listed on the survey, one practical implication for physicians is to keep a copy of this survey so that they can formally request such accommodations for their patients. It would be helpful for parents to also have a copy so that they can be aware of what they may request on behalf of their child with lupus. School counselors and school psychologists should also be acquainted with this list since they will encounter more patients with lupus during their careers.

**Implications for Future Research**

The level of resilience displayed by the students with lupus inspires wonder as to how they were able to achieve such good grades despite battling a life-threatening chronic illness. Questions regarding factors which contribute to their resiliency would be good to answer, since it may offer some helpful insight which may assist children with other forms of chronic illness.

Future research may also incorporate medical aspects into future studies, such as using bloodwork to examine specific blood counts. The student's health can be correlated with school-related accommodations in order to tease out which accommodation has the best direct effect on their health. Researchers can use bloodwork to determine the effectiveness of specific school placements as well, such as the patient's participation in the "Resource Specialist Program" (RSP) or a special day class. A possible question could be "Would pediatric patients who are on
chemotherapy exhibit less inflammation in the classroom or in the home/hospital program?"

Having the bloodwork numbers can more accurately confirm or deny the effectiveness of a chosen variable. Since lupus patients are required to have regular bloodwork to examine their physical condition, it would be beneficial to have them journal regularly about school and a correlational study can be conducted on the relationship between bloodwork and school.

Research also should be conducted with college students (young and older adults) regarding the accommodations they may be receiving. Given that college students with disabilities often receive less support than younger students which may result in undue stress, research is warranted on the types of accommodations that college students receive and perceive to be useful.

The biggest hurdle to obtaining such answers involves the collaboration between school psychologists and physicians. That type of partnership is necessary for future studies in pediatric school psychology to be conducted. The research fusion of medicine and education would be beneficial for students with medical conditions, so that their quality of life can be improved and their resilience can be optimized.

**Conclusion**

Providing accommodations to students with disabilities is a legal and ethical approach to support their educational endeavors. The present study examined the accommodations and accommodation preferences of students with systemic lupus erythematosus in order to learn which accommodations are most effective, according to their experience and perspectives. One accommodation stood out from the rest, and that was having extended time to complete assignments. Since this was a favorite accommodation from the lists of given accommodations and ideal accommodations, it is recommended that this accommodation be considered when
writing a 504 plan or IEP for a child with lupus. Although the sample size of the present study is small and lacks statistical power, the high frequency of this accommodation choice caused it to stand out from other accommodations.

Even though extra time on assignments was the leading choice among the rest of the accommodations, it is important to remember that accommodations are a very personalized and individualized form of academic support. Any established accommodation should focus on the specific needs of the child in the school environment. The accommodation does not need to have research backing for it to be attempted, because every child with lupus has unique medical and educational needs. Increasing the public's awareness of such needs may offer direct or indirect support to all students, with systemic lupus erythematosus or other chronic conditions, so they may have the opportunity to achieve their goals.
References


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Today's Dietician, 11(11), 38.


Hiraki, L., Lu, B., Alexander, S., Shaykevich, T., Alarcón, G., Solomon, G.,


Rekvig, O. & Van Der Vlag, J. (2014). The pathogenesis and diagnosis of systemic lupus


adolescents and young adults with systemic lupus erythematosus. *Arthritis Care and Research*, 68(6), 828-837.


and disease and damage in systemic lupus erythematosus. *Journal of Rheumatology*, 28(3)525-532


APPENDICES

Appendix A

IRB Approval from Children’s Hospital of Orange County

From: Shannon Tanaka <STanaka@choc.org>
Date: Thu, Jun 20, 2019 at 2:06 PM
Subject: RE: Email for Dr. Shulman
To: Seng <seng100@mail.chapman.edu>
Cc: Megan Bailey <mebailey@choc.org>

Hi MaryAnn,

That sounds great. Again, as long as zip code is removed from the surveys, it would not be considered human subject research therefore would not require any additional review through our IRB.

Let me know if anything changes or if you or Dr. Shulman have any additional questions.

Best of luck with everything.

Thanks,
Shannon

Shannon Tanaka
Manager, Research Programs
Children’s Hospital of Orange County
Research Institute
1201 W. La Veta Avenue
Orange, CA 92868
Email: stanaka@choc.org
Cell: 949-292-3123
Office: 714-509-7534
Fax: 714-509-4318
Appendix B

IRB Approval from UCLA’s Mattel Children’s Hospital

--------- Forwarded message ---------
From: Lillig, Paul <PLillig@research.ucla.edu>  
Date: Tue, Jun 25, 2019 at 6:55 AM  
Subject: UCLA IRB Review Not Required  
To: Seng <seng100@mail.chapman.edu>

Thank you MaryAnn.

We have determined that UCLA IRB review is not required for your research project titled “The Perceived Effectiveness of School-Based accommodation for students with Systemic Lupus Erythemosus”.

Please consider my dated signature on the attached document the formal notice of this determination.

Thank you,

Paul Lillig  
NGIRB Administrator  
310.206.2091  
plillig@research.ucla.edu
Appendix C

IRB Approval from Cottage Hospital
Appendix D

IRB Approval from Chapman University
Appendix E

Content Validation Protocol
(If you are completing this form, please do NOT complete the survey again during the actual study.)

Thank you for carefully examining this survey for the purpose of improvement. Please feel free to write your edits and/or ideas directly on the attached survey. Please rate the statements below and write any input which you may have. Thank you for your participation and ideas!

(Awful) ☹️☹️☹️ 5 4 3 2 1 ☺️☺️☺️ (Perfect)

The purpose for the survey is valid.  

The directions on the survey are understandable.  

The wording of the items are clear to me.  

Response options to the questions were logical.  

The order of the items are appropriate.  

The list of possible accommodations are comprehensive.  

Items on the survey were not offensive.  

The length of the survey was reasonable.  

The accommodation(s) which should have been included in the accommodation list is/are:

________________________________________________________________________

________________________________________________________________________

Themes/Topics which should have been included are:

________________________________________________________________________

________________________________________________________________________
Themes/Topics which should not have been included are:

____________________________________________________________________________________

____________________________________________________________________________________

Additional Ideas to improve the quality of the survey:
Appendix F

PARENT INFORMED CONSENT TO PARTICIPATE IN ANONYMOUS SURVEY RESEARCH

PLEASE read this consent form before choosing whether to allow your child’s participation. Because the research involves an anonymous survey and does not include any personally identifying information, your written permission will not be required. By allowing your child to complete the survey you are providing permission to the researchers to use the responses in our research. You may assist your child in completing the survey. We thank you for your consideration.

IRB #:  

_The IRB will add this number when your application is approved._

Title of Study:

_The Perceived Effectiveness of School-Based Accommodations for Students with Autoimmune Conditions_

Members of the Research Team

<table>
<thead>
<tr>
<th>Lead Researcher: Randy Busse, Ph.D.</th>
<th>Office: 714-997-6783</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student Researcher: MaryAnn Seng</td>
<td>Cell Phone: 714-862-6290</td>
</tr>
</tbody>
</table>

Key Information

_This is a request for your consent for your child to participate in a research study that examines secondary students' accommodations at school. Only secondary students (middle & high school) or parents of a secondary student with lupus may participate. Please complete only one survey per family. You are not required to complete this anonymous survey. Your medical care is not dependent upon the completion of this survey. If you agree to allow your child to answer the survey questions, the task can be completed in about 15 minutes. You may help your child to complete the survey. You or your child may choose to skip any question/item. The level of risk is minimal. If you encounter any problems with the survey, please contact the research contact person, MaryAnn Seng at 714-487-4500. There is no compensation for participation. Please keep this consent form for your records._
Invitation

Parent(s) of Middle and High School Students: Please consider participating in this study about school and students who have an autoimmune condition. The following information will provide further detail about the study. Feel free to contact the researcher at 714-487-4500 if you have any questions.

Why are you being asked to be in this research study?

The study focuses on middle and high school students who have an autoimmune condition and their accommodations at school.

What is the reason for doing this research study?

The reason for the study is based on the fact that autoimmune conditions are most often diagnosed during the adolescent years. Very few studies have focused on pediatric autoimmune patients, particularly involving the topic of school accommodations. Thus, an examination of school accommodations may help us better understand pediatric patients' physical well-being and educational success.

What will be done during this research study?

In the clinic’s waiting room, secondary school patients will be encouraged to take a brief survey about their school programs and accommodations. The questions focus on your child’s educational programs, current accommodations and preferred accommodations. You may assist your child in the completion of the survey. The survey is anonymous, therefore you will not be asked to provide any personally identifying information about yourself or your child. You or your child may skip any item if you do not wish to respond to it.

How will my information be used?

The anonymous survey responses will be used by the researchers in order to gather information about school accommodations for children with autoimmune conditions.

What are the possible risks of being in this research study?

As with any study involving the collection of data, there is the possibility of breach of confidentiality. Other risks include possible emotional and/or psychological distress.
because the surveys involve sensitive questions about your child’s medical condition and treatment.

There are no known risks to you or your child for being in this research study.

What are the possible benefits to you or your child?

There are no benefits for participation in this study.

What are the possible benefits to other people?

Children with autoimmune conditions may benefit from the findings of this study, which may provide schools with information regarding accommodations that may help young patients to succeed in the educational environment.

What are the alternatives to being in this research study?

There are no alternatives to participation. You may choose not to participate.

What will participating in this research study cost you?

There is no cost to you to be in this research study.

Will you be compensated for being in this research study?

You will not be compensated for your participation in this research study.

What should you do if you have a problem during this research study?

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the beginning of this consent form.

How will information about you be protected?
Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. Because the surveys are anonymous, your responses are unidentifiable.

The data will be stored electronically through a secure server and will only be seen by the research team during the study and for 10 years after the study is complete.

The only people who will have access to your research records are the members of the research team, the Institutional Review Board (IRB), and any other person, agency, or sponsor as required by law. Information from this study may be published in scientific journals or presented at scientific meetings but the data will be reported as group or summarized data and your identity will be kept strictly confidential.

Please note that all Chapman University employees are required to report any known or suspected abuse of children or minors to appropriate authorities.

What are your rights as a research subject?

You may ask any questions about this research and have those questions answered before agreeing to participate in the study or during the study. For study related questions, please contact the investigator listed at the beginning of this form. For questions concerning your rights or complaints about the research, contact the Chapman University Institutional Review Board at (714)628-2833 or irb@chapman.edu.

What will happen if you decide not to be in this research study or decide to stop participating once you start?

You can decide not to be in this research study, or you can stop being in this research study (i.e., "withdraw") at any time before, during, or after the research begins for any reason. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with your physician, the investigator or with Chapman University. You will not lose any benefits to which you are entitled.

Documentation of informed consent

By allowing your child, with or without your help, to complete this anonymous survey you are providing consent for participation. Please keep this form for your records.
Appendix G

CHAPMAN UNIVERSITY ASSENT TO PARTICIPATE IN RESEARCH

School-Based Accommodations for Students with Lupus

Participating in this study is totally voluntary. Please read about the study below. Feel free to ask questions about anything that you do not understand before deciding if you want to be in the study. A researcher listed below can answer your questions.

Principal Investigator: Randy T Busse, PhD Chapman University

Phone: 714-997-6783; email busse@chapman.edu

Contact Person: MaryAnn Seng

Phone: 714-487-4500; email seng100@mail.chapman.edu

Why am I asked to be in this study?

A research study is usually done to find a better way to treat people or to understand how things work. You are asked to participate in this study because you are in middle school or high school and you have lupus. It is important to understand lupus in the context of school since you spend a lot of time in that setting.

What should I know about a research study?

You do not have to be in this study if you do not want to do so. It is up to you if you want to participate. You can choose not to take part now and change your mind later if you want. Your decision will not be held against you. You can ask all the questions you want before you decide.

Why is this research being done?

In this study, we want to find out more about how teens with lupus feel about the different ways their schools help them.

How long is this study?

Your participation will only involve an anonymous survey that can be completed in 15 minutes.

Do I have to be involved in the study?

You do not have to be in the study. This study is not part of your healthcare. No one will be mad at you if you don’t want to do this. If you don’t want to be in this study, you do not have to complete the survey. If you want to be in this study, first ask your parent if it is ok and then
complete the survey [your parent can help you with parts of the survey that you cannot answer]. You can say "yes" now and change your mind later. It is up to you to decide.

**What happens if I say “Yes, I want to be in this research”?**

If it is okay with you and you agree to join this study, you will be asked to complete an anonymous survey [your parent can help] in your physician's waiting room. You will provide some information about yourself like your age and gender, medications you might be taking, and list your present school-based accommodations and your preferred accommodations. Accommodations are those things the school does for you to help you because you have lupus.

After you complete the survey place it in the lock box in the waiting room under the sign that asks you to participate. **Do not put your name on the survey.**

**Is there any way being in this study could be bad for me?**

You may feel uncomfortable with some of the questions, but it most likely will not cause any pain or negative feelings. You may skip any question and you may stop any time.

**What happens to the information collected for the research?**

The information will be used to help us understand how to better help students who have lupus in school. The surveys are anonymous, so your name or identity will not be available to anyone.

**Will you get better if you are in the study?**

No, the study will not benefit you or help you, but the information may help us help students like you in the school setting.

**Who can I talk to?**

If you have any questions about the study or any problems to do with the study you can contact MaryAnn Seng 714-487-4500.

If you have questions about the study but want to talk to someone else who is not a part of the study, you can call the Chapman University Institutional Review Board (IRB) at (714)-628-2833.

**Confidentiality:** We have ethical obligations to contact individuals to help you if you should threaten to harm yourself. If keeping information obtained in this study private would immediately put you in danger, we will release that information to protect you.

Now that you know about the study, if you complete the survey you are giving your permission to be part of the study. Thank You!!!
Appendix H

Spanish Assent Form

ASENTIMIENTO PARA PARTICIPAR EN LA INVESTIGACIÓN
Adaptaciones escolares para estudiantes con Condiciones autoinmunes
Participar en este estudio es totalmente voluntario. Lea sobre el estudio a continuación.
No dude en hacer preguntas sobre cualquier cosa que no entienda antes de decidir si desea participar en el estudio. Un investigador enumerado a continuación o su médico, la Dra. Miriam Parsa, pueden responder sus preguntas.

Investigador principal: Randy T Busse, PhD Chapman University
Teléfono: 714-997-6783; correo electrónico busse@chapman.edu

Persona de contacto: MaryAnn Seng
Teléfono: 714-487-4500; correo electrónico seng100@mail.chapman.edu

¿Por qué me piden que participe en este estudio?
Por lo general, se realiza un estudio de investigación para encontrar maneras mejor de tratar a las personas o comprender cómo funcionan las cosas. Se le pide que participe en este estudio porque está en la escuela intermedia o secundaria y tiene una enfermedad autoinmune. Es importante comprender las condiciones autoinmunes en el contexto de la escuela, ya que pasa mucho tiempo en ese lugar.

¿Qué debo saber sobre un estudio de investigación?
No es necesario que participe en este estudio si no desea hacerlo. Depende de usted si desea participar. Puede elegir no participar ahora y cambiar de opinión más adelante si lo desea. Su decisión no se tomará en su contra. Puede hacer todas las preguntas que desee antes de decidir.

¿Por qué se está haciendo esta investigación?
En este estudio, queremos saber más sobre cómo se sienten los adolescentes con condiciones autoinmunes sobre las diferentes formas en que sus escuelas los ayudan.

¿Cuánto dura este estudio?
Su participación solo implicará una encuesta que tomará aproximadamente 15 minutos en completarse.

¿Tengo que participar en el estudio?
No tienes que estar en el estudio. Este estudio no es parte de su atención médica. Nadie se enojará contigo si no quieres hacer esto. Si no desea participar en este estudio, no tiene que completar la encuesta. Si desea participar en este estudio, primero pregunte a sus padres si está bien y luego complete la encuesta [sus padres pueden ayudarle con partes de la encuesta que no puede responder]. Puede decir "sí" ahora y cambiar de opinión más tarde. Usted decide.

¿Qué sucede si digo "Sí, quiero participar en esta investigación"?
Si está de acuerdo con usted y acepta unirse a este estudio, se le pedirá que complete una encuesta. Proporcionará información sobre usted, como su edad y sexo, los medicamentos que podría estar tomando y enumerará sus acomodaciones actuales basados en la escuela y sus las adaptaciones preferidas. Las adaptaciones son aquellas cosas que la escuela hace para ayudarle porque tiene una enfermedad autoinmune. No tendrá que proporcionar ninguna información que pueda identificarlo como su nombre o código postal.

Después de completar la encuesta, doble el papel por la mitad y colóquelo en la caja cerrada en el consultorio de su médico. No ponga su nombre en la encuesta.
¿Hay alguna forma de participar en este estudio que pueda ser malo para mí?
Puede sentirse incómodo con algunas de las preguntas, pero lo más probable es que no le cause ningún dolor o sentimientos negativos. Puede omitir cualquier pregunta y puede detenerse en cualquier momento.

¿Qué sucede con la información recopilada para la investigación?
La información se usará para ayudarnos a comprender cómo ayudar mejor a los estudiantes que tienen lupus en lugares escolares. Las encuestas son anónimas, por lo que su nombre o identidad no estará disponible para nadie.

¿Mejorará si está en el estudio?
No, el estudio no lo beneficiará ni lo ayudará, pero la información puede ayudarnos a ayudar a estudiantes como usted en lugares escolares.

¿Con quién puedo hablar?
Si tiene alguna pregunta sobre el estudio o cualquier problema relacionado con el estudio, puede comunicarse con MaryAnn Seng 714-487-4500.

Confidencialidad: tenemos obligaciones éticas de contactar a las personas para ayudarlo en caso de que amenace con lastimarse. Si mantener en privado la información obtenida en este estudio lo pondría en peligro de inmediato, divulgaremos esa información para protegerlo.

Ahora que conoce el estudio, si completa la encuesta, está dando su permiso para ser parte del estudio. Gracias.
Appendix I

Spanish Consent Form

CONSENSUIMIENTO INFORMADO DE LOS PADRES PARA PARTICIPAR EN LA INVESTIGACIÓN DE ENCUESTA ANÓNIMA

La efectividad percibida de las adaptaciones escolares para estudiantes con enfermedades autoinmunes

Investigador principal: Randy Busse, Ph.D., Universidad Chapman
Teléfono: 714-997-6783; correo electrónico busse@chapman.edu

Estudiante Investigador: MaryAnn Seng, Universidad Chapman
Teléfono: 714-487-4500; correo electrónico seng100@mail.chapman.edu

Lea este formulario de consentimiento antes de elegir si desea permitir la participación de su hijo/a. Debido a que la investigación involucra una encuesta anónima y no incluye ninguna información de identificación personal, no se requerirá su firma por escrito. Al permitir que su hijo complete la encuesta, está dando permiso a los investigadores para usar las respuestas en nuestra investigación. Usted puede ayudarle a su hijo/a a completar la encuesta. Le agradecemos por su consideración.

Información clave
Esta es una solicitud de su consentimiento para que su hijo/a participe en un estudio de investigación que examina las adaptaciones para los estudiantes en la escuela secundaria. Solo pueden participar estudiantes de secundaria (escuela secundaria y escuela intermedia), o padres de estudiantes de secundaria, con lupus. Por favor complete solo una encuesta por familia. Esta encuesta anónima, no necesita escribir su nombre participacion. Su atención médica no depende de la finalización de esta encuesta. Si acepta permitir que su hijo responda las preguntas de la encuesta, la solicitud se puede completar en aproximadamente 15 minutos. Usted puede ayudar a su hijo/a a completar la encuesta. Usted o su hijo/a pueden optar por omitir cualquier pregunta / artículo. El nivel de riesgo es mínimo. Si tiene algún problema con la encuesta, comuníquese con la persona de contacto de la investigación, MaryAnn Seng, al 714-487-4500 o con su médico, la Dra. Miriam Parsa. No hay compensación por la participación. Guarde este formulario de consentimiento en sus registros.

Invitación
Padres de estudiantes de secundaria y escuela intermedia: considere participar en este estudio sobre la escuela y los estudiantes que tienen una enfermedad autoinmune. La información que sigue proporcionará más detalles sobre el estudio. No dude en comunicarse con el investigador al 714-487-4500 si tiene alguna pregunta.
¿Por qué se le pide que participe en este estudio de investigación?
El estudio se enfoca en estudiantes de secundaria y escuela intermedia que tienen una condición autoinmune y reciben acomodaciones en la escuela.

¿Cuál es la razón para hacer este estudio de investigación?
La razón del estudio se basa en el hecho de que las afecciones autoinmunes se diagnostican con mayor frecuencia durante los años de la adolescencia. Muy pocos estudios se han centrado en pacientes autoinmunes pediátricos, en particular sobre el tema de servicios en la escuela. Por lo tanto, un examen de las adaptaciones escolares puede ayudarnos a comprender mejor el bienestar físico y el éxito educativo de los pacientes pediátricos.

¿Qué se hará durante este estudio de investigación?
En la sala de espera de la clínica, se alentará a los pacientes de la escuela secundaria contestar a una breve encuesta sobre sus programas y adaptaciones escolares. Las preguntas se centran en los programas educativos de su hijo, las adaptaciones actuales y las adaptaciones preferidas. Puede ayudar a su hijo a completar la encuesta. La encuesta es anónima, por lo tanto, no se le pedirá que proporcione información de identificación personal sobre usted o de su hijo/a. Usted o su hijo/a pueden omitir cualquier elemento si no desean responderlo.

¿Cómo se usará mi información?
Los investigadores utilizarán las respuestas anónimas de la encuesta para reunir información sobre lugares escolares para niños con afecciones autoinmunes.

¿Cuáles son los posibles riesgos de participar en este estudio de investigación?
Al igual que con cualquier estudio que involucre la colección de datos, existe la posibilidad de violación de confidencialidad. Otros riesgos incluyen posibles trastornos emocionales y / o psicológicos porque las encuestas involucran preguntas delicadas sobre la condición médica y el tratamiento de su hijo/a.

No hay riesgos conocidos para usted o su hijo/a por participar en este estudio de investigación.

¿Cuáles son los posibles beneficios para usted o su hijo?
No hay beneficios por participar en este estudio.

¿Cuáles son los posibles beneficios para otras personas?
Los niños con afecciones autoinmunes pueden beneficiarse de los resultados de este estudio, que puede proporcionar a las escuelas información sobre las adaptaciones que pueden ayudar a los pacientes jóvenes a tener éxito en el entorno educativo.

¿Cuánto le costará participar en este estudio de investigación?
Puedes elegir no participar.
No tiene ningún costo participar en este estudio de investigación.

¿Serás compensado por estar en este estudio de investigación?
No será compensado por su participación en este estudio de investigación.

¿Qué debe hacer si tiene un problema durante este estudio de investigación?
Su bienestar es la principal preocupación de cada miembro del equipo de investigación. Si tiene un problema como resultado directo de participar en este estudio, debe comunicarse de inmediato con una de las personas enumeradas al comienzo de este formulario de consentimiento.
Appendix J
Spanish Survey

ENCUESTA ESCOLAR ANONIMA

Complete esta encuesta si es padre de un estudiante / o si es un paciente que se encuentra actualmente en la escuela intermedia (secundaria) o preparatoria. Por favor entregue solo una encuesta por familia. Al completar esta encuesta, le está dando permiso al investigador para incluir sus respuestas en el estudio. Por favor imprima sus respuestas claramente. NO ponga su nombre en la encuesta. Una vez que haya respondido a cada elemento en nombre del paciente, coloque la encuesta en el recuadro bloqueado marcado "Encuestas completadas". ¡Muchas gracias por su tiempo y participación!


Origen étnico del estudiante: ___________________________________________  Género:  M  F  Otro

¿Cuál es el ingreso familiar total antes de impuestos en 2018?  (Circule uno)
0- $20,000  $20,001- $40,000  $40,001- $60,000  $60,001- $ 80,000  $80,001+

¿Diagnóstico actual del estudiante:
_________________________________________________________________________________________

¿Está el estudiante tomando esteroides?  Si  No

Nombre de esteroide: ____________________________  MG total por día: ________________

¿Está el estudiante actualmente en quimioterapia (IV o pastillas)?:  Si  No

Frecuencia de la quimioterapia: ___________________________________________________________

¿Tiene el estudiante un Plan 504 en la escuela?  Sí  No  No se

¿Tiene el estudiante un Programa de Educación Individualizado (IEP)?  Si  No  No se

Si se ha implementado un IEP, verifique cada servicio que el paciente recibe actualmente:

__ Programa de especialistas en recursos   __ Terapia ocupacional   Otro: ________________

__ Clase de educacion especial   __ Terapia física   ________________

__ Consejeria   __ Orientación y movilidad   ________________

__Educación física adaptativa   __Servicios de habla / lenguaje   ________________

En general, mis maestros siguen los arreglos especiales, como se delinea en mi Plan 504 o IEP, a una tasa estimada de:  (Deje esto en blanco si no tiene acomodaciones establecidas)

0%  10%  20%  30%  40%  50%  60%  70%  80%  90%  100%
Por favor verifique todos las acomodaciones especiales que su escuela ha proporcionado durante el presente año escolar:

1. Asientos preferenciales  
2. Descanso para el baño según sea necesario  
3. Uso de equipo adaptativo para tareas  
4. Permitir tiempo extra entre clases  
5. Excusa de actividades durante enfermedad activa  
6. Tardanzas de la mañana en la escuela pueden ser justificadas  
7. Estirarse según sea necesario  
8. Uso de un ascensor/elevador en la escuela  
9. Transporte a / desde la escuela  
10. Audio-grabar conferencias / presentaciones  
11. Permitir respuestas/reportes verbales  
12. Permiso para usar gorro/sombrero en clase  
13. Puede ver a la enfermera de la escuela según sea necesario  
14. Tiempo adicional para completar  
15. Permitir el acceso al protector solar en la escuela  
16. Colección extra de libros para usar en casa  
17. Limitar la exposición al sol  
18. Descansar según sea necesario  
19. Software de escritura de voz  
20. Mantener desinfectante de manos en el escritorio  
21. Sentarse en un escritorio con estilo cómodo  
22. Provisión de resúmenes / presentaciones  
23. Día escolar acortado según sea necesario  
24. Permiso de usar guantes según sea necesario

De la lista numerada anterior, ¿cuáles 3 acomodaciones especiales son más útiles? (Por favor escriba el número que corresponde a sus elecciones.)

Primera opción: ________ Segunda elección: ________ Tercera Elección: ________

¿Qué 3 arreglos especiales serían ideales para su condición? [Se pueden elegir entre las opciones anteriores, ya sea que estén marcadas o no, y / o puede escribir otros arreglos especiales.]

Primera opción: ________________________________________________________________

Segunda opción: ________________________________________________________________

Tercera opción: ________________________________________________________________

Esta encuesta fue completada por [circule una]:

- Paciente
- Padre/ Guardián del Paciente
- Los Dos (Paciente y Padre/ Guardián)
Please complete this survey if you are a middle-school or high-school student. Your parent/guardian may help you complete the survey or they can complete it for you. By completing this survey, you are giving the researcher permission to include your answers in the study. Please print your answers clearly. DO NOT put your name on the survey. After you have answered each item, please place the survey in the locked box marked “Completed Surveys”. Thank you very much for your time and participation!

Student’s Age: _______ Grade: _______ G.P.A.: _______ Gender (circle): Male Female Other

Student’s Ethnic Background: __________________________________________

What is the family’s total household income before taxes in 2018?
0-$20,000 $20,001-$40,000 $40,001-$60,000 $60,001-$80,000 Above $80,000

Student’s Current Diagnosis: __________________________________________

Is the student taking steroids?: Yes No

Steroid Name: ____________________________ Total MG per day: __________________________

Student’s Other Medications (and dosage):
________________________________________________________________________
________________________________________________________________________

Is the student currently on chemotherapy (IV or pills)?: Yes No

Frequency of chemotherapy: ____________

Does the student have a 504 Plan at school? Yes No Don’t know

Does the student have an Individualized Education Program (IEP)? Yes No Don’t know

If an IEP is in place, please check each service that the student currently is receiving:

_ Resource Specialist Program
_ Counseling
_ Occupational Therapy
_ Orientation & Mobility
_ Special Day Class
_ Adaptive Physical Education
_ Physical Therapy
_ Speech/Language Services

Other: __________________________

In general, my teachers follow the accommodations, as outlined in my 504 Plan or IEP, at an estimated rate of:

(Leave this blank if you do not have established accommodations)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Please check every accommodation which your school has provided during the present school year:

___1. Preferential Seating
___2. Bathroom breaks as needed
___3. Use of adaptive equipment for assignments
___4. Allow extra time between classes
___5. Excuse from P.E. activities during active disease
___6. Morning tardiness at school can be excused
___7. Stretch as needed
___8. Use of an elevator at school
___9. Transportation to/from school
___10. Audio-record lectures/presentations
___11. Allow verbal answers/reports
___12. Permission to wear hat in class
___13. Can see school nurse as needed
___14. Extra time to complete assignments
___15. Allow access to sunscreen at school
___16. Extra set of textbooks for use at home
___17. Limit sun exposure
___18. Rest as needed
___19. Voice-typing software
___20. Keep hand sanitizer on desk
___21. Sit in a comfortable style of desk
___22. Provision of outlines/presentations
___23. Shortened school day
___24. Permission to wear gloves as needed

Other: __________________________________________________________________________________________

From the numbered list above, which 3 accommodations are most helpful? (Please write the number which represents your choices.)

First Choice: _________
Second Choice: _________
Third Choice: _________

Which 3 accommodations would be ideal for your condition? [These may be chosen from the options above, whether checked or not, and/or you may write in other accommodations.]

First Choice: ______________________________________________________________________________________
Second Choice: _____________________________________________________________________________________
Third Choice: ______________________________________________________________________________________

This survey was completed by [circle one]:

Student                  Student's Parent/Guardian                Both (Student and Parent/Guardian)
Glossary of Terms

Anti-Ifnar: A substance/drug that blocks interferon-alpha's receptor

Anti-Nuclear Antibody: an antibody that targets and binds to regular proteins within a cell’s nucleus; A significant amount of ANA’s may signal autoimmune disease

Aseptic meningitis: Inflammation of the tissues covering the brain and spinal cord

Autoantibody: An antibody that mistakenly identifies a “self protein” as being a foreign entity

Central Nervous System: Consists of the brain and spinal cord, which acts as a command center to control other bodily systems

Corticosteroid: A steroid hormone that is produced by the adrenal cortex or their synthetic equivalents; Various types produce different effects (such as alleviating inflammation)

Cytopenia: Occurs when one or more of the blood cell counts are lower than normal; There are different types (e.g. Anemia is a type of cytopenia involving red blood cells, Leukopenia is a type involving white blood cells)

Cytotoxic: Producing a destructive or toxic effect on cells

Cutaneous: Involving the skin

Cytokine: A general term for hormone-like proteins which are released by various cells types to regulate immune response and cell communication

Epidemiology: The branch of medicine which focuses on the cause, incidence, distribution, and control of disease in a population

Hematology: The branch of medicine that focuses on the diagnosis and treatment of diseases of the blood and blood-forming tissues

Hemoglobin: A complex protein in red blood cells which carries oxygen via iron molecules; The main role is to transport oxygen from the lungs to body tissue
IFNAR (Interferon-Alpha): A small protein cytokine that acts like an alarm by triggering extra immune activity when it binds with numerous receptors in different tissues

Immunosuppression: suppression of the immune system's response

Incidence: The rate or risk of contracting a new disease during a particular timeframe

Ischemic Stroke: One of the three main types of strokes that occurs when an artery in the brain is blocked

Monoclonal antibody: A copy of a laboratory-produced antibody/parent cell which can be designed to bind to a specific substance

Morbidity: The frequency or number of individuals who have a particular disease

Mortality: The rate or risk of death in a population

Myasthenia gravis: An autoimmune condition where the body attacks its own tissues, particularly the connection between the nerve and the muscle

Nephrology: The study of kidney function and disease

Nephritis: Inflammation of the kidneys

Pathogenesis: The biological origination and development of a disease

Phenotype: The observable and measurable characteristics or an organism that is a physical expression of the genes

Platelet: Colorless, disk-shaped cell fragments in the blood that are involved in blood clotting

Polychlorinated biphenyls (PCB’s): A group of compounds used in the manufacture of plastics and fluids used to coat metal, concrete, and wood; Manufacture of PCB's was stopped in 1977 due to its toxicity to human health and the environment

Prevalence: The proportion of the population who has a disease during a particular timeframe
Psychoneuroimmunology: The study of how the brain, the nervous system, and the immune system impact each other

Pulsing: The administration of a high dose of corticosteroids for a few days and tapering it down or dropping it back to the low dose prior to the pulsing period

Rheumatology: The study of rheumatic conditions, such as arthritis, gout, tendinitis, and lupus