The Barriers of Systemic Lupus Erythematosus that Affect Self-Efficacy for Physical Activity

A Thesis submitted to the faculty of San Francisco State University In partial fulfillment of the requirements for the Degree Master of Science In Kinesiology

by

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December 2022
Certification of Approval

I certify that I have read The Barriers of Systemic Lupus Erythematosus that Affect Self-Efficacy for Physical Activity by Emily Jane Pica Peralta, and that in my opinion this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirement for the degree Master of Science in Kinesiology at San Francisco State University.

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Abstract

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease that targets organ systems like the renal, central, and cardiopulmonary systems. SLE is the number one leading cause of death among women due to the illness and its comorbidities. Lupus requires lifetime management and care. Physical activity is crucial for treating patients with lupus, as previous studies have shown improvements in fatigue, pain, and overall quality of life. However, there is still a lack of participation in physical activity among patients with lupus. Therefore, this study aims to discover the obstacles presented by living with lupus that affect individuals’ self-efficacy for physical activity. Data collection was done through semi-structured one-on-one interviews with 6 young adult women with lupus. Findings revealed that all participants experienced shock, fear, and uncertainty from their diagnosis due to a lack of guidance and information about the disease. A lack of energy, pain and mental barriers refrained these participants from engaging in physical activity. However, their support system and their desire to manage their lupus healthily served as a facilitator to participate in physical activities.
Acknowledgements

I thank all the participants with Systemic Lupus Erythematosus for sharing their experiences in the interviews. I would also like to thank Dr. Maria Veri, Dr. Nicole Bolter, and Dr. Jimmy Bagley for their guidance and support. Lastly I would like to thank my parents, family, friends, and dogs for supporting me throughout this enlightening experience.
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Introduction

What is Lupus?

Systemic Lupus Erythematosus, or Lupus, has made headlines within the public health community within the last couple of years because of public figures announcing their recent or ongoing diagnosis. Despite the publicity, there is a lack of public health education about this debilitating disease. Over 60% of Americans know little to nothing about this chronic illness, where there are over 1.5 million cases in the United States alone (2019 Lupus Awareness Survey 2019). There are four different types of Lupus: Systemic Lupus Erythematosus, Cutaneous Lupus, Drug-Induced Lupus, and Neonatal Lupus. Systemic Lupus Erythematosus is the most common form of Lupus. Cutaneous Lupus is a form of Lupus that is only limited to the skin. Drug-induced Lupus is a Lupus-like disease caused by certain prescription drugs. Neonatal Lupus is a rare condition that affects infants of women who have Lupus (What is Lupus? 2020). For this Literature Review, I will be focusing solely on Systemic Lupus Erythematosus and referring to it as lupus or SLE.

Lupus is an incurable chronic long-term disease that can cause several health problems and impact an individual’s quality of life. According to the CDC, the seriousness of lupus can range from mild to life-threatening. Lupus patients often experience many complications that can affect their bodies for different periods of time (Centers for Disease Control and Prevention 2020). Lupus is categorized as a prototypic autoimmune disease, as it can attack the healthy tissues of the body and affect the way the body fights infections (Pessato et al 2018). Lupus is also a chronic inflammatory disease associated with exacerbations and remissions within a broad spectrum ranging from very mild forms to major organ involvement that can cause significant
morbidity and mortality (Kinikli 2021). Lupus can affect the body both physically and mentally, with symptoms ranging from mild to severe.

**Signs, Symptoms, Causes:**

There is not a single sign that can indicate a diagnosis of lupus, which makes lupus challenging to diagnose. Lupus itself can cause various symptoms that vary between each individuals. Common symptoms include extreme fatigue, joint pain, and an erythematous flat or raised rash across the bridge of the nose and cheeks called a butterfly rash. The primary pathological findings in patients with Lupus are inflammation, vasculitis, immune complex deposition, and vasculopathy (Mok et al 2003). An individual may also experience swelling, muscle pain, tenderness, hair loss, anxiety, and depression. Fatigue is one of the most prevalent symptoms of SLE, affecting up to 90% of individuals even when the disease is in remission. In chronic conditions of lupus, fatigue is reported by individuals to be one of their most burdensome symptoms and one that impacts the most on their quality of life (O’Riordan et al 2017). The cause of lupus is still unknown. For professionals to distinguish how an individual got lupus, they would probably look through family medical history since lupus can run in the family. However, experts also speculate that lupus can develop due to environmental triggers and/or responses to certain hormones, but overall there is no known specific cause for lupus.

**Who is at Risk?**

Although lupus can affect anyone at any age, the population at highest risk is women between the ages of 15 and 44. There are specific ethnic groups that are also at a higher risk for lupus; these include but are not limited to individuals who are African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander. People who have a family
member with lupus or another autoimmune disease are also at risk for Lupus. (What is Lupus? 2020).

**Comorbidities**

Being diagnosed with lupus can cause other problems associated with the disease. Lupus can target specific areas and tissues of the body. The joint, renal, central nervous, and cardiopulmonary systems are usually compromised, and systemic manifestations can trigger symptoms such as fatigue, malaise, fever, nausea, anorexia, weight loss, and hair loss, consequently reducing the quality of life and, in some cases, leading to death (Fanouriakis et al 2021). Lupus is one of the most complex and complicated connective tissue diseases. Lupus causes various debilitating symptoms, but it can also affect different internal organs of the body, causing additional health problems. It is quite common that individuals with lupus will have to manage other major health problems that can coexist with it. People with lupus most likely have to manage other autoimmune diseases that coexist with it, such as hemolytic anemia, immune thrombocytopenic purpura, and thyroiditis. In addition, advances in treatment cannot prevent deaths associated with comorbidities.

**Lupus and Cardiovascular Risks**

Patients with lupus are at a 3x higher risk for cardiovascular diseases when compared to the population (Angelica et al 2013). Compared to other rheumatic or chronic illnesses, lupus patients have a two-fold higher number of atherosclerotic plaques in the carotid and femoral arteries, which is comparable to the enhanced risk of cardiovascular disease for people with rheumatoid arthritis and diabetes mellitus. Individuals with lupus also have a two-fold increased rate of ischemic stroke or myocardial infarction compared to the general population. With the high significant risk of cardiovascular disease in lupus patients, it is speculated that it could be
due to immune dysregulation. Both dysregulations of innate and adaptive immune responses can contribute to the high prevalence of cardiovascular disease in lupus. In addition, arterial stiffness, when the arteries or blood vessels become stiffer and are related to hypertension, is significantly elevated in people with lupus (Liu et al., 2018). It is because of lupus and its complications and comorbidities like cardiovascular disease that lupus is one of the leading causes of death among young women (Boström et al 2016).

**Lupus and Quality of Life**

Managing lupus and other health-related problems can affect how an individual is able to perform and enjoy activities of daily living. In terms of quality of life, physical and mental health-related quality of life are reduced among patients with lupus. Maintaining a high-level quality of life can be difficult with severe symptoms of pain, fatigue, weakness, and more. Musculoskeletal pain affects 50-61% of lupus patients, with morning stiffness affecting about half and fatigue affecting up to 60-90% of people with lupus (Sheikh et al 2019).

**Fatigue**

Previous studies have assessed fatigue within individuals with lupus and found that it plays a significant role in their quality of life. Fatigue can affect many lupus patients; fatigue is still present even in a remission state. “The etiology of fatigue in the SLE population is multifactorial and is associated with physical activity, obesity, sleep quality, depression, anxiety, mood, cognitive dysfunction, vitamin D deficiency/insufficiency, comorbidities such as fibromyalgia, or related to the SLE disease” (Ahn et al 2012 page 2). Fatigue itself is considered a comorbidity in patients with lupus. There are two types of chronic fatigue: central and peripheral. Peripheral fatigue is known as physical fatigue, in which the peripheral nerves are impaired and defects muscular contraction. Central fatigue is associated with abnormalities in
neurotransmitter pathways within the central nervous system and is also related to psychological complaints like depression or anxiety. Individuals with lupus suffer from central and peripheral fatigue (Pettersson et al 2015).

Fatigue substantially impacts an individual’s ability to perform self-care activities such as washing and dressing. It has also been shown to impact participation in social and leisure activities negatively. In a qualitative study on the effects of SLE-related fatigue on occupational participation, study participants reported no difficulties in self-care. Still, they identified a range of productivity and leisure activities that caused them problems (O’Riordan et al 2017).

Previous studies have examined the relationship between quality of life and fatigue in patients with lupus. In a study by Pettersson et al, the researchers surveyed individuals with lupus assessing their fatigue severity using different self-reporting questionnaires, lupus activity measure (to assess disease activity), and health-related quality of life questionnaire. The results indicated that the patients with high levels of fatigue also had high disease activity, indicating that the more severe their disease is, the more fatigue a person can have (and vice versa). The study also found high levels of anxiety and depression among the participants with Lupus compared to the general population (Pettersson et al 2015).

Treatment

Unfortunately, since there is no known cure for lupus, it requires lifetime management and care. A lot of treatment for lupus is for symptom relief. As mentioned before, individuals with lupus experience a tremendous amount of pain, swelling, fatigue, anxiety, and depression, as well damage to the skin, joints, and organs like the kidney, heart, brain, nerves, blood vessels, and lungs. The main goal of treatment is to prevent flare-ups (heightened symptoms that cause the individual to fall ill), provide symptom relief, reduce swelling, pain, and damage to the joints,
and reduce organ damage and other problems. Since lupus is an auto-immune disease, the treatment must help calm the immune system from further attacking organs and tissues in the body.

**Medicinal Treatment**

According to the CDC, there are different treatments in terms of medicines used to treat lupus. The type of treatment varies between each individual. Corticosteroids (pills, injections, creams) are also used to help reduce swelling, tenderness, and pain. They can also help calm the immune system, and typically the lupus symptoms respond quickly. However, the longer an individual is on corticosteroids, the harder it is to lower the dose and stop the medicine. Antimalarial drugs, like hydroxychloroquine, can prevent or treat joint pain, skin rashes, fatigue, and lung inflammation. Studies have shown that antimalarial medication can stop lupus flares and may help people with lupus live longer. Chemotherapy can be used in severe cases of lupus in instances where other treatments do not work. However, chemotherapy can have severe side effects because they lower the body’s ability to fight off infections. Other medicines may need to be prescribed due to the additional illnesses linked to lupus-like heart disease, high blood pressure, osteoporosis, and arthritis (Centers for Disease Control and Prevention 2020).

**Exercise and its Role for Patients with Lupus**

Despite the symptoms and comorbidities that individuals with lupus must manage, it is highly recommended to participate in physical activity. With the increased risks of cardiovascular disease and related illnesses, exercise is beneficial to add to a patient's lupus treatment plan. Exercise can help reduce the risk of mortality due to the disease itself and / or the associated comorbidities. According to both the World Health Organization (WHO) and Physical Activity Guidelines for Americans, adults with chronic conditions have the same
recommendations as those without, which is 150 minutes a week of physical activity, with added caution of supervision by a provider (Molina et al 2021). The American Heart Association and American College of Sports Medicine recommend regular moderate-intensity physical activity as an efficient method for the prevention and complementary treatment of several diseases. Evidence indicates that regular exercise improves vascular function and reduces cardiovascular risks of lupus (Kao et al 2021).

**Previous Studies**

The importance of physical activity for an individual’s health has been emphasized since ancient times. However, physical activity still plays a significant role worldwide. A lack of participation in physical activity is the fourth leading factor for global mortality. However, sedentary behavior puts individuals at high risk for cardiovascular, metabolic, and cancer-related mortality and morbidity (Margiotta et al 2018). People with lupus are shown to be physically inactive based on the activity recommendations by the World Health Organization. In a study by Margiotta et al (2018), the researchers evaluated the proportion of people with lupus who did not meet the World Health Organization recommendations for physical activity. They assessed the amount of time spent on sedentary behavior. The results indicated that 60% of the participants in this study were performing physical activity below the World Health Organization’s recommendation of 150 minutes of physical activity a week. The results also showed that one-third of their participants spent more than 4.5 hours a day in sedentary activities. Patients with lupus are already associated with cardiovascular disease and mortality, but having high numbers of sedentary engagement daily can further increase this risk. Also, disease activity was assessed through the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI), a clinical index for measuring disease activity for individuals with lupus. The participants that spent a long time
in sedentary behavior had increased disease activity and a prevalent number of flare-ups. (Margiotta et al 2018).

Exercise plays a significant role in treating and managing lupus and its symptoms. Alongside medical treatment, physical activity has been emphasized as a form of treatment for helping individuals with lupus maintain their physical fitness while also increasing their quality of life. However, there is a lack of physical activity and a prevalence of a sedentary lifestyle for individuals with lupus. Previous studies have shown that exercise can play a vital role in managing not only lupus but also its comorbidities. Cardiovascular and cognitive impairments are important issues in lupus patients. These problems may be worsened further by the physical inactivity of SLE patients who are less willing to or prohibited from engaging in physical activity due to disease complications. Still, evidence has shown that physical activities can improve cognitive performance. Adding exercise as a form of therapy with medical treatment has shown benefits for treating patients with lupus. In a study conducted by Kao et al (2021), where the researchers evaluated a 12-week aerobic and resistance training program among physically inactive women with mild lupus, results demonstrated the value of exercise among physically inactive women. The 12-week combined exercise program significantly improved physical fitness and executive function in lupus patients without exacerbating their disease status.

In another study conducted by Kinikli et al (2021), researchers wanted to assess lupus disease activity utilizing specific questionnaires where the participants had to self-report their physical activity levels, capacity, anxiety, depression, and quality of life. The study found that patients who reported low physical ability were older, had longer disease duration, more organ damage, and revealed a lower overall quality of life, less mobility, less usual activities, more pain, and depressive symptoms. Patients with low physical capacity also reported being less
physically active and exercising less than those who reported higher physical capacity. Participants who had an early diagnosis of lupus and were younger had higher physical capacity when compared to those who had longer disease duration and more organ damage; they had a much lower physical capability. This study also showed that other than musculoskeletal manifestations and cardiopulmonary involvement, fatigue, fibromyalgia, and depression had been presented as barriers to physical activity for people with lupus (2021).

Previous research involving prescribing aerobic physical activity to individuals with lupus showed statistically significant improvements in body pain reduction, fatigue, and quality of life. So, in a study conducted by Sheikh et al (2019), the researchers wanted to evaluate the effectiveness of a six-week walking program for individuals with lupus. The researchers for this study used self-reported questionnaires to receive the participants’ feedback on the walking program and how it has impacted their quality of life. This study was the first to do a walking program for individuals with lupus specifically. Previous studies have utilized this walking program for those with other rheumatic conditions, and those studies have reported an improvement in symptoms in terms of pain, stiffness, and fatigue. The research study showed that the 6-week walking program could successfully reduce pain, stiffness, and fatigue symptoms in lupus patients and potentially improve quality of life. The results of these studies add additional literature regarding an exercise program for individuals with mild, moderate, and possibly severe cases of lupus. Importantly, for the potential uptake of this program by patients with SLE, walking has been a preferred form of exercise by lupus patients (2019).

Aerobic exercises such as walking and biking are the most favorable forms of physical activities among people with lupus, but that does not mean that individuals with lupus should shy away from other types of physical activity. In a study by Abrahão et al (2016), the researchers
wanted to compare resistance training versus cardiovascular training to see the effectiveness in improving the quality of life and physical function of people diagnosed with lupus. The study involved questionnaires that assessed lupus disease activity and quality of life. The exercise intervention consisted of a 12-week program of 3 groups; one that received cardiovascular training via walking and stationary bicycle, one that received resistance training via free weights and resistance bands, and the third group was the control group that received usual care and education on lupus but no exercise intervention (Abrahão et al 2016). This study showed that both exercise intervention groups improved their quality of life. The results also indicated no significant differences in disease activity, indicating that the participants did not feel like their lupus got worse. Disease activity is one of the many limiting factors why patients with lupus are hesitant to exercise (Abrahão et al 2016).

Fatigue, as mentioned before, has a significant impact on people with lupus. Fatigue can be an aggressive circle regarding a person’s physical activity engagement. In a randomized control study by Tench et al (2003), the researchers evaluated the symptomatic and functional changes associated with patients with Lupus participating in a 12-week program of a control, aerobic exercise therapy, or relaxation therapy intervention. The primary key finding of this study showed that after 12 weeks of the intervention programs, there was a significant improvement in fatigue among the participants in the aerobic exercise therapy group. In a cross-sectional study by Mahieu et al (2016), the researchers investigated the relationship between fatigue and daily physical activity. The researchers found that the increased time spent in physical activity correlates with less fatigue and more physical function among their participants with Lupus (Mahieu et al 2016). The results make it evident that there can be overall
improvement by appropriately prescribing exercise to manage fatigue while also not exacerbating disease activity among patients with Lupus.

Exercise training, alongside medicinal treatment, can help alleviate symptoms in patients with Lupus. Exercise training alone can also help an individual with Lupus in terms of physical fitness. Physical fitness is the ability to carry out daily tasks with vigor and alertness without undue fatigue and with ample energy to enjoy leisure time and meet unforeseen emergencies. A review article from our group (Yuen et al 2016) found that exercise training can improve physical fitness and aerobic capacity, physical function, and quality of life in Lupus patients. The increased aerobic capacity is associated with increased maximal oxygen consumption, also known as VO2 max. The VO2 max indicates the maximum amount of oxygen the body can use during exercise. Aerobic fitness training can increase VO2max, which is associated with a lower risk of mortality and morbidity in patients with Lupus (Yuen et al 2016).

**Why is There a Lack of Participation?**

Numerous studies utilize different forms of exercise training for individuals with Lupus that show the positive effects of exercise. Aerobic physical activity has been correlated with decreasing pain and fatigue and increasing physical function and quality of life. On top of that, since patients with Lupus are at a 2-3x higher risk for cardiovascular disease, engaging in physical activity is beneficial because it can increase cardiopulmonary and cardiorespiratory fitness (Giannelou et al 2017). Being physically active would help individuals with Lupus carry out activities of daily living and benefit their quality of life. Despite the known benefits of exercise and being physically active, many individuals with Lupus still spend more time sedentary. The question remains, why is there a low rate of engagement in physical activity among patients with Lupus?
**Common Limiting Factors**

Fatigue, is the most prevalent symptom among patients with Lupus, affecting up to 90% of patients. Fatigue can lead to a decreased drive to participate in exercise because its severity can make it extremely difficult to move around, let alone exercise. Severe fatigue could lead a person with Lupus to become sedentary for multiple hours of the day. However, the longer an individual remains in a sedentary state and reduces their physical activity levels, this could only worsen fatigue and disease activity over time (Margiotta et al 2018). This vicious cycle of having severe fatigue can be a difficult barrier that individuals with Lupus have trouble overcoming. This study emphasizes that prolonged periods of being in a sedentary state can lead to adverse health outcomes among patients with Lupus, potentially worsening their disease and engagement in physical activity.

In a pilot study conducted by Mancuso et al (2011), the researchers wanted to analyze individuals with Lupus’ perspective regarding physical activity. The researchers asked open-ended questions about the participant's opinions on physical activity. The main finding was that many of the participants did not participate in physical activity because of the possibility of making their symptoms worse (joint pain, fatigue, etc.). Also, the patients noted that other common barriers, like the absence of time, weather, and undesirable exercise facilities contributed to their lack of participation. The patients in this study did recognize that there are potential benefits to physical activity, but they did not know what steps to take to overcome these barriers (Mancuso et al 2011). This study shows that physical pain is one of the most significant limiting factors to physical activity, but being aware of the benefits but not knowing how to overcome these barriers means more needs to be done in terms of guidance for patients with Lupus.
Lupus is a serious illness that not everyone seems to understand its effects on a person. Lupus can impact an individual’s day-to-day life in many different ways. In a qualitative study by Mattsson et al (2012), the researchers investigated the negative impacts of Lupus on everyday life. The researchers wanted to understand how much Lupus interfered with their day-to-day life. The key findings of this study were that having an “unreliable body” was a significant limiting factor for individuals with Lupus. The participants noted having a lot of uncertainty about how they were feeling, how their bodies would react to treatment, or whether or not they were experiencing a flare-up (Mattsson et al 2012). This study highlights the unpredictability of Lupus in everyday life. A person’s uncertainty about their ability to carry out tasks is an essential barrier to recognizing among Lupus patients. A person with Lupus may want to participate in different activities, but their body is not as reliable where pain, fatigue, exhaustion, and flare-ups can appear out of nowhere. These limiting factors are possibilities why a person with Lupus does not engage in too much physical activity because of the possibility of exacerbating any symptoms.

The role of social support for people with Lupus can be both positive and negative. It is crucial to remember that Lupus is not necessarily a “visible” disease. There are no visible cues that can make someone look like they have Lupus. Since the symptoms of Lupus are not necessarily visible, sometimes the social support from others can be reduced. However, some other forms of social support can be overbearing and can negatively affect the person with Lupus rather than helping them. In a study conducted by Brennan et al (2016), the researchers explored the different perceptions of the quality and impact of social support for patients with Lupus using open-ended survey questions. The key findings of this study were that people with Lupus felt invisible due to unseen symptoms, which tied into feelings of loneliness. Individuals with Lupus
felt alone, and the negative responses to their diagnosis, like disbelief, minimizing their symptoms, hindered them from seeking support from others. These feelings also lead to decreased quality of life (Brennan et al 2016). This study draws attention to the social environment surrounding individuals with Lupus and how vital education on this illness is, especially for those who have or are close to others with Lupus. The actions and behaviors of others can significantly affect an individual’s quality of life with Lupus.

**Self-Efficacy and Lupus**

Self-efficacy is a theory used to understand why someone is or is not motivated to participate in a particular context. Self-efficacy takes an interactive approach to motivation whereby a person’s behavior depends on their individual characteristics and the environment (Bandura 1977). Lupus can affect a person’s self-efficacy and motivation to engage in physical activity. A person can say they have self-efficacy for exercise, but that can easily get derailed because of the barriers individuals with Lupus face. Self-efficacy affects behavior, but it also affects people’s cognitions. For example, higher self-efficacy for tasks, which is a self-perception, might correlate to higher self-esteem. Likewise, higher self-efficacy for a task might also have more positive mood states or less trait anxiety (Bandura 1977). So, if patients with Lupus have high self-efficacy for physical activity, it would benefit them physically and cognitively.

It is essential to recognize the psychological components that Lupus and all illnesses have on an individual and their quality of life. It is necessary to be educated on how the environment (physical and social) can affect someone with Lupus. In a longitudinal study by Mazzoni et al (2017), researchers utilized web-based surveys to analyze if perceived self-efficacy plays a role in managing Lupus and quality of life. This study showed a significant impact of self-efficacy on
quality of life. The findings show that greater self-confidence and perceived self-efficacy lead to more positive outcomes like increased quality of life (Mazzoni et al 2017). The research indicates that perceived self-efficacy can positively affect individuals with Lupus in managing their disease and positively affecting their quality of life. It is important to take information from this research and see how the results can be used to increase an individual’s perceived self-efficacy when it comes to physical activity. If patients with Lupus can have access to psychoeducational interventions to enhance their self-efficacy, this can positively affect their participation in physical activity.

If enhancing self-efficacy can lead to positive outcomes, then it is possible that low perceived self-efficacy can lead to adverse effects among patients with Lupus. In a cross-sectional study by Somers et al (2012), the researchers utilized questionnaires to examine how pain-coping cognitions of self-efficacy for pain control were related to physical symptoms and psychological distress in patients with Lupus. This study showed a relationship between low levels of self-efficacy with increased physical symptoms and psychological distress. These results suggest that patients with Lupus who have low perceived self-efficacy for pain control are more likely to report pain, stiffness, and fatigue (Somers et al 2012).

It is essential to recognize how significant counseling and education are for people diagnosed with Lupus. In a randomized controlled trial conducted by Kankaya et al (2020), the researchers wanted to determine the effectiveness of web-based counseling and education for patients with Lupus on self-efficacy, fatigue, and assessment of care. Participants were put into an educational intervention program where they were taught about everything Lupus-related. The results showed that the web-based program caused a significant increase in self-efficacy among the participants and a reduction in the level of fatigue (Kanakaya et al 2020). These results
indicate the positive effects of higher self-efficacy and decreased fatigue levels. Having proper guidance and education on Lupus could have a positive impact on a patient with Lupus self-efficacy for physical activity.
**Purpose**

According to these studies, patients with Lupus’ perceived self-efficacy can be directly related to the ability to manage the disease, symptom control, and quality of life. The most common barriers that affect people with SLE are symptoms of pain, fatigue, flare-ups, a restrictive lifestyle, and poor social support (Sutanto et al 2013). It is a possibility that these barriers and other limiting factors can also hinder an individual’s perceived self-efficacy, which can, in turn, also be correlated to a lack of engagement in exercise, but this would need further research.

There have been drastic changes in medicine, therapies, and other treatment methods for Lupus within the last decade, but exercise remains a critical component. Physical activity is a crucial factor in treating individuals with Lupus. However, a majority of people diagnosed with Lupus rarely meet the recommended physical activity amount. Previous research studies examine the exercise barriers that individuals with Lupus face. There is also previous research on people with SLE and the effects of perceived self-efficacy and quality of life. Therefore, the purpose of this study is to discover the barriers of Systemic Lupus Erythematosus that affect an individual’s self-efficacy for physical activity.
**Significance of the Study**

If we were to look into the first initial treatment methods for Lupus compared to now, there have been improvements in treating individuals with SLE. The evolution of medicine, therapies, and remedies is astonishingly different from how treatment used to be over a decade ago. Participating in physical activity is a significant factor that can help manage symptoms, increase physical fitness, and increase the quality of life for people with this incurable, debilitating disease. However, after all these improvements in treatment and emphasis on physical activity, there is still a low participation rate in exercise and a prevalence of sedentary behavior among patients with Lupus. Individuals with SLE face many physical and psychological barriers that can have a negative impact on their bodies.

Over 60% of Americans know little to nothing about this disease; this study can help provide updated information, spread awareness, and educate the general public about patients' Systemic Lupus Erythematosus and the limiting factors that affect their self-efficacy to get better potentially. Previous qualitative studies on common and psychological barriers were conducted over a decade ago. With the recent COVID-19 pandemic, this could also play an important role in the lack of participation of Lupus. There needs to be updated information on the obstacles that individuals with Lupus face today, especially with the advances in medicinal and exercise prescriptions. Previous studies have researched the effects of self-efficacy, but they do not tie the relation to the low rates of physical activity and increased sedentary behavior. Therefore, the significance of this study to investigate the barriers that affect self-efficacy for physical activity will be beneficial information for individuals with Lupus, healthcare teams, families, friends of patients, and the general population.
Personal Narrative

This topic is quite personal to me. Over two years ago, during the COVID-19 pandemic, I was experiencing a lot of pain, fatigue, and stiffness in my joints. I have a past medical diagnosis of a rare form of arthritis, but this pain was significantly different. After falling very ill and being admitted to the hospital, I found out that I was experiencing symptoms of Lupus and was later formally diagnosed with mild Systemic Lupus Erythematosus. It was challenging to accept that I had another medical problem that I had to try and overcome. I have this high level of anxiety because of the uncertainty and unreliability of my body. Every second of every day was a mystery in terms of my body. Fortunately, I have an excellent medical team and support system that has helped me throughout this whole journey. On top of that, I have access to an education where I learned more about my disease and the importance of physical activity. After all, I am lucky because of the excellent support system and all this knowledge engraved in my brain that motivates me to be physically active because I know it will help me manage my lupus.

Not everyone has the resources that I have. There is a lack of awareness about the physical and psychological effects of lupus on patients, doctors, and the overall population. A majority of people with lupus felt alone and misunderstood. Even I still have this feeling despite the resources I have access to. I think it is essential to have more recent research on this topic because it does take a village to help people understand and overcome the barriers that affect people with Lupus. Any examination of this disease is one step closer to finding the cure.
**Methodology**

**Participants**

In-depth qualitative, one-on-one, semi-structured interviews were conducted for this study. The participants were over the age of 18, residing in the United States, and formally diagnosed with Lupus by a physician. The participants had been diagnosed with Lupus for at least over one year. Participants with additional health problems because of Lupus were welcomed into the study. However, individuals with physical injuries were excluded because this could be a potential barrier (that is not related to Lupus) to a lack of physical activity. The participants could be sedentary or engage in less than 150 minutes of exercise per week within the last three months in order to collect data on the barriers of physical activity. However, individuals with Lupus who were physically active could participate in this study as well. This inclusion helped give insight on the facilitators of physical activity.

**Procedures**

This qualitative study utilized one on one semi-structured interviews that took approximately 45 minutes. For health and safety precautions regarding COVID-19, interviews were conducted virtually via Zoom or other video conferencing methods accessible to the participants. I created various open-ended questions formed, as well as completed a bracketing and pilot interview to assess validity. During the bracketing interview, I sat down with two members of my thesis committee with qualitative expertise and was interviewed using my interview guide. Along with the bracketing interview, I conducted a practice pilot interview to assess validity. The recruitment of participants was done via social media through advertisements in online support groups. I utilized a support group that was created on Meta that has over 30,000 members who were diagnosed with lupus from all over the world. I created a
virtual poster that displayed the need for participants as well as stating the inclusion criteria. Those who expressed interest and met the criteria were contacted with further information on the research study. If the person agreed to become a participant, we scheduled a date and time to conduct the interview. Before the day of the interview, each of the participants had to sign an Informed Consent form stating that they consent to having the interview audio and video recorded and were also informed on the possible risks of the study. After signing the Informed Consent form, the interview would take place.

**Data Collection**

Once consent was obtained, the interviews took place. After all the interviews were conducted, the transcription of these interviews started. Each interview was transcribed and coded for themes that will help answer our research question.

**Data Analysis**

In order to formulate themes, I analyzed the data by taking notes throughout the interview and highlighted any information they shared that was relevant to the research question. After each interview was completed I went back to listen and watch the audio and video recording and transcribed each interview. After the transcription was completed, I highlighted impactful quotes from the participants and formulated themes that were common throughout each interview and helped answered our research question.

On top of transcribing, coding, and forming a thematic analysis; I also analyzed the participants for specific nonverbal cues. It was essential as a qualitative researcher to analyze not only verbal cues, but to look into nonverbal cues as well. According to Onwuegbuzie et al, “nonverbal communication data could allow qualitative researchers to (a) corroborate speech narrative (i.e., triangulation); (b) capture underlying messages (i.e.,
complementarity); (c) discover nonverbal behaviors that contradict the verbal communication (i.e., initiation); (d) broaden the scope of the understanding (i.e., expansion); and (e) create new directions based on additional insights (i.e., development). This conceptual framework indicates that qualitative researchers can use nonverbal communication data for one or more of five purposes relative to the verbal communication data collected, either a priori (e.g., looking for contradictions between the nonverbal and verbal data from the onset), a posteriori (i.e., determining how the nonverbal and verbal data relate to each other as the data analysis unfolds), or iteratively (i.e., combining a priori and a posteriori analyses)” (2014).

Since the interviews were conducted via Zoom, it was highly recommended for the participants to keep their cameras on in order to obtain nonverbal data. While conducting the interview, I took notes on their answers, as well as the nonverbal cues that I observed. After the interview was finished, I looked back at the video recording and took more notes on their nonverbal cues. The nonverbal data added onto the rich in-depth information that I had already obtained.
Findings

Participant Profiles

When recruiting for the study, there were about 25 individuals that expressed interest in the study. Out of the 25 people, 19 of them met the criteria to be an eligible participant. There were 10 interviews scheduled. However, 2 participants were unresponsive and failed to show up to the interview and did not reschedule. Another 2 participants were unable to participate in the interview due to flare ups from their lupus that made it difficult for them to participate. A total of 6 participants were able to complete the interview.

All of the participants were young women between the ages of 20-45 residing in different areas of the United States. All of the participants had a formal diagnosis of systemic lupus erythematosus, along with other underlying health problems that occurred because of lupus. The interview ranged from 30-45 minutes and was held virtually through an online conferencing platform of their choice.

Alex Biography

Alex is an individual in their mid-twenties who has been formally diagnosed with systemic lupus erythematosus for 6 years. Alex resides in Illinois and developed several underlying health conditions like Stevens-Johnson syndrome (SJS), anemia, toxic epidermal necrolysis, and Crohn's disease because of lupus. Alex has also experienced being put in a medically induced coma because of the negative side effects of treatment for lupus. However, Alex uses her online platform to educate the public on lupus by sharing her amazing story on different social media platforms. Her story was featured on local news channels, and has received positive feedback from many netizens. She is also a newlywed who got married within the last month and is looking forward to growing her family with her husband.
**Jamie Biography**

Jamie is an individual in their mid-forties who has been formally diagnosed with systemic lupus erythematosus for 4 years. Jamie resides in California and does not have any current underlying conditions or health problems that developed because of lupus. However, Jamie does frequently experience intense common symptoms of lupus since being diagnosed. Jamie is a wife and mom of two wonderful kids. Despite her demanding job, she is looking forward to putting more emphasis on self-care in the near future.

**Jordan Biography**

Jordan is an individual in their late thirties who has been formally diagnosed with systemic lupus erythematosus for 8 years. Jordan resides in Florida and developed some underlying health problems because of their diagnosis with lupus. Within the last 8 years Jordan has developed high blood pressure, and kidney problems. Jordan is a realtor that also loves to powerlift. She has participated in strong woman competitions and is looking forward to setting a new personal record in powerlifting. She was able to powerlift up to 500 pounds!

**Eden Biography**

Eden is an individual in their early thirties diagnosed with systemic lupus erythematosus for 5 years. Eden resides in New York and has developed some health problems since their diagnosis. Within the last 5 years, Eden’s lupus has progressed into lupus nephritis and developed into kidney problems, but it is manageable. Eden has taken her experiences with lupus, became an ambassador for the Lupus Organization, and uses her online platform to educate people about lupus. She loves traveling and just recently got married! Eden is looking forward to having a “plus one” for life.
**Elliot Biography**

Elliot is an individual in their early twenties who has been diagnosed with systemic lupus erythematosus for 6 years. Elliot resides in Massachusetts and has developed underlying health conditions due to the lupus diagnosis. Within the last 6 years, Elliot has developed rheumatoid arthritis and angioedema, which are common health problems that arise with lupus. Elliot is currently attending college and is a cheerleader for her school. She has a ballet background that has been a massive help since she enrolled in cheerleading this year. Elliot also loves sharing her lupus story on social media platforms and has grown a big following within the past year.

**Kris Biography**

Kris is an individual in their late twenties who has been formally diagnosed with systemic lupus erythematosus for 14 years. Kris resides in Nevada and has developed some underlying illness due to the lupus diagnosis. Within the last 14 years, Kris has developed Sjorgens, autoimmune hemolytic anemia, and basal skin cancer. Kris was diagnosed at a young age, but she was a competitive basketball player and dreamed of playing in college. Although she was diagnosed with lupus early in high school, she continued her passion and played all four high school years. Despite her diagnosis, Kris uses the power of social media to share her story and help educate other members of the lupus community on ways to help manage the disease. She even started her own support group in her area as well.
Thematic Analysis

The participants of this study provided rich, in-depth details on their experiences with lupus, physical activity, and more. There were several common themes that a majority of the participants had that were similar, whether it would be their experiences, emotions, or physical symptoms. Six themes emerged from the study that highlighted the participants' experiences from their first official diagnosis to how it has affected their engagement in exercise and how it has impacted their quality of life.

Absolutely No Idea

When the participants were first experiencing various symptoms like pain, fatigue, and swelling, they sought answers to understand what was happening to their bodies. When they were all informed that they had an autoimmune disease called lupus, they all explained being confused, shocked, and unaware of their future. When asked about their knowledge of the disease before being diagnosed, Elliot mentioned she “absolutely no idea” what the disease was or how it would alter her life, and being “confused more than anything else.” Jamie stated, “I had no exposure to lupus before… have never read about it… there’s not a lot of information out there.” All of the participants did not know how to cope with being diagnosed. The lack of information and education on the disease had them thinking it was not a big deal until their doctors gave them more information or they looked it up on the internet. The feeling of confusion was similar among the participants. Alex also mentioned that she “didn’t grasp it at the moment.” It is safe to say that they experienced a roller coaster of emotions. Some were emotional, like Eden, who “broke down crying,” while Kris “felt very defeated” upon learning their diagnosis. These participants originally went to see their doctor to seek answers, but it, unfortunately, was not the answer they were expecting at all. Lupus is a mysterious disease that
experts are still trying to figure out. It is not easy being told you have this illness, and there is not much information about it. The reactions of confusion, shock, and fear among these participants are not at all surprising.

**Loss of Energy/Independence**

Since being diagnosed, all participants had to adjust to an entirely new and unfamiliar lifestyle. Many participants have to deal with life-long symptoms of pain, fatigue, discomfort, and much more. One of the most significant changes that all the participants experienced was a lack of energy. They explained that before their diagnosis, they could do many physical and social activities, but since the diagnosis of lupus, it has changed dramatically. Alex explained that before, she had “unlimited energy.” Still, after the diagnosis of lupus, she would often “budget” her energy if she wanted to be able to participate in any events throughout the day or week. Jordan stated, “no matter how much rest I would get, I would still be tired. I was always so depleted, I had no energy to do anything.” They all got an official diagnosis at a young age, so it was challenging to have their lifestyle change rapidly. This loss of energy affected their lifestyle and the choices they would make on a day-to-day basis. Their loss of energy contributed to their loss of independence. Sometimes they would not have enough energy to do everything they need and would often rely on help from others.

**Barriers to Physical Activity**

Physical activity is essential in an individual with a lupus treatment plan. Before having lupus, most participants had their favorite forms of physical activity, like dancing, walking, basketball, and more. Many of them were very active before being diagnosed. After having lupus for quite some time, most participants had to change or find a different routine suited to their
bodies and needs. However, they all have physical and mental barriers that affect their motivation to participate in physical activity.

Alex stated, "[the impact of lupus] affected me more negatively; there are certain things I found that I can't do anymore, like running." Jamie said that she has "given up" on exercising entirely but is working on returning to it in the future. Physical symptoms like joint pain, fatigue, tiredness, and flare-ups are essential factors that contribute to the barriers affecting their motivation to exercise. Elliot mentioned how even the mildest flare-ups are considered a "normal bad day," but a "really bad-bad day, there's usually joint pain and headaches." Alex talked a bit about tiredness, saying, "when I'm feeling tired, I'm feeling tired. There's no convincing me…even when getting more than 12 hours of rest/sleep when our body has a flare up we have no control over it, unfortunately." Eden shared, "if the pain is too much… I can't handle it… it's definitely the physical pain that's going to be the most demanding." These statements show how unpredictable this disease is and how much it can take a toll on the body. Despite getting more than enough rest, unfortunately, it may not be enough. This disease takes away their sense of control over their own body. Jordan firmly stated, "I just felt like my life was passing me by. I think that was the worst part of that, I really wanted to actively participate in life, but I physically couldn't." Many of them emphasized that physical pain played a hindrance to their willingness to exercise, but also in their ability to live life the way they wanted to.

The intensity of the physical symptoms of lupus varies in different ways, but lupus can also affect you mentally. Many of the participants faced mental obstacles that affected their willingness to exercise. Kris stated, "I definitely got in my head about not being as much anymore… I'm not strong enough compared to everyone else in the gym." Kris talked about how lupus "really sets you back… you feel way behind. So I feel like that's when I get really in my
head." Jordan mentioned, "I think that the biggest hindrance is mental… I was frustrated." Jordan also shared that "when I was first diagnosed, I truly think that I did have some moments of depression. I think I felt like well, I'm young; I have chronic illness forever. I'm going to die with this disease and this disease might kill me early. I was really thinking about the morbid specs, like am I gonna die tomorrow? It was really making me freak out." Physical barriers like swelling, pain, and tiredness are visible to the eye, but it is vital to consider the mental barriers that people with lupus face. It takes a lot of physical strength to recover from various symptoms of lupus, but it also takes a lot of mental strength.

**Facilitators for Physical Activity**

Although there are many obstacles that people with lupus must overcome to motivate themselves to get up and participate in physical activity, there are different motivators that play the role of facilitators of physical activity. A common finding that served as a motivator for many participants was self-reflection and visualizing a better tomorrow. When Eden was reflecting on her lupus journey, she stated, "I just remember how I was feeling back then, and just to see how far I've already progressed, there's so much more I want to do with my future… that's what sort of keeps me motivated, like, have the potential to do so much, and I don't want to waste that potential." Jordan vocalized "my number one motivation is that I don't like being told that I can't do something. I don't like being told no. If it pushes me, it drives me to be like, no, I can do that! Because even though I may have this disease, this disease doesn't have me. I'm not going to stop living my life." Another finding was that there is a desire to be healthy. Kris mentioned, "I tried many different things. I tried weightlifting, I've tried yoga, tried, you know, biking. And I just think it's about finding your groove. And that really motivates me, because I
know how it's healthy for me." Before Jamie had taken a break and was exercising, she reasoned, "I'm doing this because I want to be healthy."

The participants mentioned other important motivators that have helped them throughout their lupus journey; their family. Kris explains, “my parents played a huge role…if I didn’t have them being as supportive, just open minded to how I was actually feeling I think that's really important is that they're able to learn and listen.” Elliot stated, “my entire family is kind of really active I guess they kind of motivated me because it's like, at this point, just a routine that we all do… [they] definitely give more tough love and I need that.” Eden mentioned, it's just more like my family. So I now just recently got married. And you know, now we're trying to think about our future. And you know, and see what that looks like. So again, everything is not just mindset of like, what can I do to better my tomorrow? And you know, the future? So I think those are my main motivation is like my family.” Kris emphasizes, “I want to be with my family, and that was a lot of great motivation.” Alex mentioned, "I want to be able to enjoy time with my family and savor [the moment]... spending time with my family and also not being a Debbie Downer.” A solid support system, whether family, friends, or peers, are significant facilitators for an individual with lupus, especially regarding physical activity. A great support team is what can help make managing a troublesome disease like lupus a bit more bearable.

The Effects of COVID-19

The global pandemic turned everyone's life upside down. The world shut down on a random mid-week afternoon, and everything since then has changed. The COVID-19 pandemic brought a lot of fear and uncertainty for everyone, especially patients with lupus. The participants of this study described experiencing a setback in their lupus journey. Jordan, who would go to the gym regularly, explained, "I stopped going because I was afraid of catching the
virus. I started going with a mask, but it was just too hard to breathe and uncomfortable doing that level of activity, so I started working out at home. After about six months, even though the gyms have been open for about two months, I didn't go back right away, because I was fearful because I'm immune compromised."

Eden, who lives in New York, where one of the first and most extensive outbreaks happened, described, "once it started getting bad, I told my manager, can I request to stay home, so I don't have to be out there with all the elements of you know, just catching anything. With the pandemic, I'm now not going out as much, and if I do go outside, I do have a mask on. I always had a mask even before the pandemic, but now I'm even more cautious." Alex, who, at the time, was recovering from Stevens-Johnson syndrome (SJS) and Toxic Epidermal Necrolysis (TEN), was relearning how to walk during the pandemic. She described, "my family decided to just put us in one house together, be isolated from everyone else, definitely wasn't able to hang out with any friends, which was awful, because I was in my recovery period at that time."

Kris, an active advocate for lupus awareness, mentioned how the pandemic shut down their local support group and stated, "it made me feel nervous to go out because I was immunosuppressed. I'm trying to do what I can to protect myself, but no one else cares. They're just, you know, not worried about other people's health. I feel like it also impacted me where I was scared to go out. So I didn't go to the gym. I didn't go to Pilates during that time, and it really slowed things down for me. Being cooped in the house isn't always great, it was tough."

Similarly, Jamie mentioned, "[when] COVID hit, I was like, well, I'm not going to the gym anymore, and I haven't been to the gym in a really long time. Now I'm, like, scared to try to do physical activity because it's been so long. I'm like, I'm gonna have to start all the way over." These individuals experienced an incredible amount of fear and setbacks from COVID-19, and
that uncertainty is still present because most of them still wear masks and do not go out as they used to.

Despite the drawbacks of the COVID-19 pandemic, some positives came about during this time. Kris had talked about getting back into exercising after the pandemic. She stated, "when I started getting more into the Pilates Reformer classes, which I'd never done before, I just started doing that this year. I found that worked better for me it's just a lot easier on my joints, and I don't have to feel like I'm pushing myself too hard. So it, in a way, made a positive change." When talking to Alex about her recovery journey from SJS and TEN during the pandemic, she explained that "ironically enough, I preferred it that way, you know, being isolated from everyone else because I wasn't comfortable. I wasn't comfortable with myself, because I changed so much physically. I took the time during the pandemic to recover. So that, which thankfully, I did, I think that… I still feel supported by my friends and family, even if I felt isolated. I hate-love relationship with a pandemic."

Another silver lining that the pandemic brought Elliot is that she stated, "I actually started [working out] around COVID, that's pretty much how I started, I was doing like a 10-minute Chloe Ting workouts, and now I do like strength training!" Even though COVID-19 had many negative impacts, the study participants took advantage of this time and turned it into a positive one. They took the chance and worked on finding exercises that work for them and recover from lupus-related health problems.

**Building Your Own Healthcare Team**

Healthcare professionals play an essential role in a patient with lupus' journey. People with lupus need to find and build a healthcare team to provide the necessary care. However, finding a healthcare team that will provide education and guidance, especially for physical
activity, is crucial. The participants were asked about the advice they were given about anything related to exercise or physical activity; surprisingly, each of their healthcare teams had various answers. Alex answered, "physical activity? I honestly don't remember them telling me much advice about anything. They're more focused on my medications, like how it's making me feel."

With Eden's healthcare team, there were some vague responses. Her healthcare team told her, "there wasn't anything that was like absolutely no, you can't do this [exercise], but try to do as much as you can."

Similarly to Eden's healthcare team, Jamie's healthcare also gave unclear responses regarding physical activity. Jamie mentioned, "they did say that that [physical activity] will really help. You know, it makes you feel better, move your body. I think though a lot I felt like they spent a lot more time talking about nutrition… I just don't have a lot of great information from my doctor." Kris's healthcare team has also had a comparable response. When asked about physical activity advice from her healthcare team, she said, "nothing that I couldn't remember actually. I just remember her being very blunt about it, that [exercise] was not a good idea."

These statements from the participants show the lack of direction from healthcare teams regarding physical activity. Unfortunately, the studies show that exercise benefits people with lupus, but these healthcare teams do not know what to prescribe.

Despite the lack of advice, there are ways for patients with lupus to advocate for their physical activity needs. Interestingly, Elliot had switched healthcare teams quite a few times because of their lack of compromise. She explained, "the only thing that they told me was to stay away from cardio… She didn't want me to do like any physical activities whatsoever…switched over to a different healthcare team: I was pulled out of dance, I actually didn't want to stop. They told me that I had to, and actually wanted to try for cheer, my sophomore year of college, and
they told me no. They finally let me do it this year.” Elliot had to switch her doctors to find one that would compromise with her. It is because she took action of her own health, Elliot received the proper guidance for her needs and was to participate in a sport that she wanted to do. Jordan had a similar experience as well. She explained, "my healthcare team, I love them very much. They've gotten me a very long way, but it was not without me advocating for my own health and my own enrichment. So initially, one of my specialists, my RA specialist, in particular, he has a more traditional approach to medicine and treating lupus. So he was more like, you know, just do very light activity, I want you to walk or do some water aerobics or yoga, no heavy weight lifting, don't go outside in the sun, don't do this, don't do that… But my nephrologist, he is actually closer in my age. So he's a little bit more modern… He was always very supportive. And when I told him that, you know, I don't want to just be regulated to doing yoga and water aerobics for the rest of my life. I really want to try something. So he encouraged me to get out there slowly, and still do the things that I love. I don't want you to stop living your life. So if you want to lift weights, then lift weights, you know, but just to, you know, gauge your tolerance and build up and things like that. So I really appreciate that from him.” If Elliot and Jordan had not advocated for their own needs, they probably would not be at the fitness level they are today. Healthcare teams need to listen to the wants and needs of their patients with lupus. Every healthcare professional managing a patient with lupus needs to help guide them in the right direction but also understand and compromise to help them have a better quality of life. To be able to advise patients with lupus about physical activity is one thing, but it is also vital to be accommodating to what they want to do.
Nonverbal Analysis

It was important as a researcher to listen to the participants on what they were willing to share, but it was also important to look into their nonverbal cues. Before the interview started, they were informed that they had every right to skip any uncomfortable question. They also had every right to stop the discussion altogether as well. I analyzed a few nonverbal cues during the one-on-one interviews: body language, voice changes, and emotional responses. It is important to analyze body language because the conversations between the researcher and the participant do not fully capture the potential data that can be collected from interviews (Onwuegbuzie et al 2014).

Body Language

Analyzing body language was interesting to look into among these participants. The way their bodies move can tell a lot, especially when they are opening up about a very vulnerable topic. Eden used their mobile device for the Zoom interview. It was hard looking into her body language because one hand was used to hold up their camera. However, whenever questions were asked about pain, she often had to readjust her position and move around a little bit to get into a relaxed state. Then she was able to start talking about her unfortunate experiences with pain.

On the other hand, Elliot positioned her camera where I could see her from the waist up, and toward the beginning of the interview, her arms were crossed during the first couple of questions. Based on how I analyzed her body language and relatively quick and short answers, this interview was probably uncomfortable for her in the beginning. However, as the interview progressed, she uncrossed her arms and opened up more, and when she started talking about her
experiences, she used her hands more as she spoke. I saw she got more comfortable as the interview went on.

Jordan had her camera where I could also see her from the waist up. There was an instance where she said this compelling statement, "even though I may have this disease, this disease doesn't have me." When she was saying this, she was slapping her hands together, which gave an added emphasis. It was almost like adding a punctuation mark after each word.

**Emotional Responses**

Getting different nonverbal emotional responses was common among the participants. A majority of the questions could be triggering to them. However, all the participants answered all the questions with courage and beauty. There were many instances where they showed frustration, irritation, and sadness, but they also showed happiness, passion, and bravery throughout the interview.

Many participants expressed frustration or heaviness in their voices when talking about the physical barriers that affect their physical activity. Alex and Eden often took deep breaths or sighed before opening up about a sensitive topic. They were willing to share so much about their experience with lupus, but they both needed to take that deep breath to prepare themselves to tell their story. In comparison, Jamie spoke with a lot of frustration regarding her diagnosis. She mentioned a lot about not knowing or getting enough information on lupus when she got diagnosed. She talked with aggravation when the sound of her voice would shift when opening up about not being appropriately guided by her healthcare team.

A support system's impact on a person with lupus is essential. On a positive note, all participants showed happiness, whether smiling, laughing, or their voices shifting into a happier pitch, whenever they talked about their support system, family, and friends. All participants felt
happiness when reflecting on their support system by smiling and chuckling when speaking about their family and friends. Alex, who experienced SJS and TEN because of lupus, lit up with so much joy when talking about her support system and how grateful she was for them, and she smiled the whole time she spoke about them. As well as Jamie, who is a mother, showed happiness whenever she mentioned her kids and was motivated because she wanted to be present for her family.

Jordan is an individual who spoke with a lot of passion, especially when talking about how she motivates herself. You can hear her voice shift into a more powerful and confident voice, especially when talking about how she will not allow lupus to control her body anymore. Throughout the interview, Jordan opened up a lot about her story and emphasized making sure to be the best version of herself every day. She did open up and was vulnerable at times throughout the interview, but what stood out was how assertive her voice was when talking about how she was changing her life for the better. All of these participants went through so much; it was an emotional and inspiring interview.
Discussion

The study's results indicate commonalities that answer the question, "why is there a lack of participation in physical activity among people with lupus?" Everyone can have various symptoms of lupus, and their body can react differently. The results indicate the physical signs of pain, fatigue, and tiredness contribute to their lack of motivation to exercise. These symptoms align with the Margiotta et al. study, where fatigue was a prevalent factor in low participation in exercise among patients with lupus (2018). Despite the physical symptoms playing a significant role in limiting the participants from engaging in exercise, the results indicated that the participants experienced mental barriers as well. Their diagnosis of lupus lead to depression, negative thoughts, fear, and less self-confidence. These mental barriers played a significant role for the participants of this study. The mental barriers contributed to having lower self-efficacy for physical activity and the participants felt discouraged from engaging in exercise.

Despite the physical and mental barriers, the participants were fortunate enough to share common facilitators that encouraged them to engage in physical activity and look forward to a better future. Unlike the Brennan et al. (2016) study, where the individuals with lupus felt discouraged from seeking support, this study showed that the participants' support system was a common facilitator among all the participants. They all had the support of their family and friends during their lupus journey, and they served as a motivator to participate in physical activity. This may be because this study had participants where their support system was more understanding of them. Another possibility is because the Brennan et al study was conducted 6-7 years ago, and since then there have been more resources accessible for families and friends to learn more about lupus and how they can help.
It was essential to analyze each participant's nonverbal cues for every question. While it was a risk that a few questions might trigger the participants because it would bring up sensitive topics, all participants were willing to open up and share their experiences for every question. The participant's body language and emotional responses showed a few significant nonverbal findings. Regarding body language, many participants were closed off and "on guard" at the beginning of the interview. They had their arms crossed and were giving relatively short answers. However, as the discussion continued, the participants were more comfortable; you could see where they uncrossed their arms and started to talk more with their hands (for example, clapping and moving arms in the air) to add more emphasis to their stories.

Another nonverbal cue analyzed in the interviews was the participants' emotional responses. Many of the emotional responses were derived from questions that led to them having to open up and be vulnerable. The participants would often take a deep breath before a rather sensitive question in a way to help prepare themselves to get ready to open up. Many participants also expressed significant frustration and aggravation when the question elicited them to recall negative experiences. Previous studies solely focus on analyzing the verbal feedback from their participants. However, this study's findings indicate a lot of value in analyzing nonverbal cues. According to Onwuegbuzie (2014), "nonverbal communication accounts for 93% of how humans communicate with each other" (p. 2). Therefore, studying the participants' nonverbal cues, such as body language and emotional responses, throughout the interviews provided more rich extensive data on top of the verbal responses. The nonverbal cues made an incredible impact because these individuals are vulnerable, and are opening up about their experiences with lupus. Their body language and emotional responses provides added emphasis to their stories. It shows
how intense this disease is and how much of an impact it has made on their life. The frustration, anger, and sadness can be seen in their body movements, and heard in their voices.

The COVID-19 pandemic has recently played a significant role in the participants’ comfort with participating in physical activity. The pandemic ironically had a mixed response in the participants’ lupus journey. Many of them experienced setbacks in managing their disease because they feared contracting the virus, which led to a slightly more sedentary lifestyle than before the pandemic. However, some participants took the opportunity to start exercising during the pandemic or took the time to rest and recover from the adverse effects of lupus. There is not much research on the effects of COVID on lupus. However, the findings of this study align with a study conducted by Sloan et al (2021). In the study by Sloan et al., it concluded that “many participants estimated their mortality risk from COVID-19 as very high and expressed great anxiety during interviews and in forum conversations.” This finding aligns with the current study that the participants were often fearful during this time and took into consideration that their top priority was to be cautious of their health.
Conclusion

Summary

The findings of this study highlight the severity of this disease and the experiences that come with it. There needs to be more education and guidance about lupus, especially regarding physical activity. The participants in this study need to be educated on the benefits of physical activity. They also need to know what type of activity to do. If they were able to find physical activities that suited their needs, there were physical and mental barriers like fatigue, tiredness, fear, and negative thoughts that contributed to low self-efficacy for physical activity. The recent COVID-19 pandemic has also affected the participants of this study. There were setbacks regarding their lupus journey, where some participants were anxious for their well-being and chose to stop engaging in physical activity for the time being. However, there were also positive outcomes from the pandemic. Some participants took this time to try out other types of physical activity or rest and recover from the harmful effects of lupus.

Opportunities for Research

All research regarding lupus is valuable. Lupus is a mysterious disease, and there is very minimal information out there because of how complex this disease is. This study can expand to healthcare professionals, and encourage them to conduct more research on prescribing exercises for people with lupus. There are also opportunities to learn more about the effects of the COVID-19 pandemic on patients with lupus. It is also essential to take this opportunity to collect more rich, in-depth data from people with lupus. With the help of qualitative research, you can build upon the current questions from this study and formulate more open ended questions regarding anything about lupus like flare-ups, developing additional health problems, holistic treatments, and so much more. Individuals with lupus are more than a statistic. Doing more qualitative
interviews gives people with lupus a chance to use their voices to share their experiences to help everyone understand what this disease does and what are the possible solutions.

**Practical Applications of Findings**

Healthcare workers need to take the findings of this study and apply them to their practice to provide the proper care and guidance for their patients with lupus. It is also vital for these healthcare workers to learn about the benefits of physical activity and how to educate their patients with lupus. Healthcare workers can take the findings from this study and learn how to prescribe exercise for individuals with lupus based on the patient’s needs. However, it is also critical for healthcare workers to compromise on what their patients want regarding their exercises to increase their quality of life. This research study will also benefit individuals recently or newly diagnosed with lupus to help them understand what is happening to their bodies. This study can also be valuable for people who are supporting a loved one with lupus. The findings of this study will help the immediate support system understand what their loved one is going through, and how they can help them. This study has contributed to the minimal research available regarding the barriers of lupus that affect an individual’s self-efficacy for physical activity. The findings of this study have contributed to the journey of finding a cure for this mysterious autoimmune disease.
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Appendices

Appendix A: Interview Guide

Before the interview begins, the researcher will thank the participant for agreeing to be a part of the study.

Dialogue: “I would like to express my gratitude and thank you for participating in this study. Your answers will help me better understand the experiences of people with lupus and physical activity.”

Warm-up Questions:
1. How old are you?
2. Where do you reside?
3. How long have you been diagnosed with lupus?
4. Do you know what form of lupus you were formally diagnosed with?
5. Do you have any underlying health problems that developed because of your diagnosis of lupus?
6. How much did you know about lupus prior to being diagnosed?

Main Questions:
1. How did you feel when you were first diagnosed with Lupus?
2. If you could, could you please describe to me what a typical “bad day” looks like?
   a. and what does a typical “good day” look like?
3. Could you describe your physical activity habits prior to being diagnosed?
   a. How did these habits change after you were diagnosed?
4. Can you describe how your diagnosis of Lupus affected (either positively or negatively) your physical activity habits?
5. After your diagnosis, can you recall what advice your healthcare team / provider gave you in terms of physical activity / exercise?
6. What are factors that play a role in your motivation to participate in physical activity?
7. Could you describe the barriers that play a role in your participation in physical activity?
8. Could you describe the facilitators that play a role in your participation in physical activity?
9. Can you explain what type of impact the COVID-19 pandemic has had on your engagement in physical exercise?
10. What advice would you give to someone who just recently got diagnosed with lupus?

Closing dialogue:
“I wanted to thank you once again for your time and your participation in this interview. I will follow up with you in a few weeks. Thank you once again, I greatly appreciate your answers and we will keep in touch”
Appendix B: Recruitment Flyer

PARTICIPANTS
NEEDED!

INTERESTED IN PARTICIPATING IN A RESEARCH STUDY ABOUT LUPUS FOR SAN FRANCISCO STATE UNIVERSITY?

IF YOU ARE:
• OVER THE AGE OF 18
• LIVE IN THE UNITED STATES
• DIAGNOSED WITH LUPUS FOR AT LEAST 1 YEAR

PLEASE DIRECTLY MESSAGE ME OR EMAIL ME AT: EPERALTA4@MAIL.SFSU.EDU

IF INTERESTED OR FOR MORE INFORMATION

THANK YOU!
Appendix C: Informed Consent Form

INFORMED CONSENT FORM
San Francisco State University
Informed Consent to Participate in Research
The Barriers of Systemic Lupus Erythematosus that affects Self-Efficacy for Physical Activity

A. PURPOSE AND BACKGROUND
The purpose of this research is to discover the barriers of lupus that affects an individual’s self-efficacy for physical activity.

The researcher, Emily Jane Peralta is a graduate student at San Francisco State University conducting research for a master’s degree/honor’s thesis at Department of Kinesiology of College of Health and Social Sciences. You are being asked to participate in this study because you are an adult residing in the United States of America with a formal diagnosis of lupus of at least one year.

B. PROCEDURES
If you agree to participate in this research, the following will occur:

- You will be interviewed for approximately forty-five to sixty minutes
- The interview will be audio and video recorded to ensure accuracy in reporting your statements.
- The interview will take place virtually via Zoom or any conferencing platform, at a time that is most convenient for you.
- The researcher may contact you later for a follow-up to clarify your interview answers for approximately twenty to thirty minutes within one month of the interview
- Total time commitment will be a maximum of ninety to one hundred and twenty minutes

C. RISKS
There is a risk of a loss of privacy. However, no names or identities will be used in any published reports of the research. Only the researcher will have access to the audio recordings, transcriptions and any other research data included. There is also a risk of discomfort, stress, or anxiety due to the nature of the questions asked. It could trigger emotional distress, however the participant can answer only those questions they choose to answer. The participant also has a right to stop participating in the research at any time without penalty.

D. CONFIDENTIALITY
The research data will be kept in a secure location and only the researcher will have access to the data, audio, and video recordings. All audio recordings will be stored in a password-protected computer. It will not be uploaded to any back up devices (ie Cloud, Google Drive, Flash-drive). When the study is completed all audio and video recordings will be wiped and trashed from the password-protected computer. Transcriptions may be kept for possible
future research purposes, but the transcriptions will not include the participants’ real identities, only pseudonyms will be used in all transcriptions.

**E. DIRECT BENEFITS**
There will be no direct benefits to the participant.

**F. COSTS**
There will be no cost to you for participating in this research.

**G. COMPENSATION**
There will be no compensation for participating in this research.

**H. ALTERNATIVES**
The alternative is not to participate in the research.

**I. QUESTIONS**
You have spoken with Emily Jane Peralta about this study and have had your questions answered. If you have any further questions about the study, you may contact the researcher by email at eperalta4@mail.sfsu.edu or you may contact the researcher’s advisor, Professor Maria J. Veri at mjveri@sfsu.edu
Questions about your rights as a study participant, or comments or complaints about the study, may also be addressed to the Human and Animal Protections at 415: 338-1093 or protocol@sfsu.edu.

**J. CONSENT**
You have been given a copy of this consent form to keep.

**PARTICIPATION IN THIS RESEARCH IS VOLUNTARY.** You are free to decline to participate in this research, or to withdraw your participation at any point, without penalty. Your decision whether or not to participate in this research will have no influence on your present or future status at San Francisco State University.

Signature _____________________________  Date: __________
Research Participant

Signature _____________________________  Date: __________
Researcher
PARTICIPANT INFORMATION  
San Francisco State University  
Informed Consent to Participate in Research  
The Barriers of Systemic Lupus Erythematosus that affects Self-Efficacy for Physical Activity

Please answer the following questions before the interview:

<table>
<thead>
<tr>
<th>Name:</th>
<th>Age:</th>
</tr>
</thead>
<tbody>
<tr>
<td>City:</td>
<td>State:</td>
</tr>
<tr>
<td>What type of Lupus were you diagnose with?:</td>
<td>How long have you been formally diagnosed with Lupus?:</td>
</tr>
</tbody>
</table>