Challenges and Coping Strategies of Children with Systemic Lupus Erythematosus (SLE)

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CERTIFICATION OF APPROVAL

This is to certify that this dissertation entitled **"Challenges and Coping Strategies of Children with Systemic Lupus Erythematosus (SLE)"** is a record of genuine work done by **Mr. Tony Thomas,** fourth semester Master of Social Work student of this college under my supervision and guidance and that it is hereby approved for submission.

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DECLARATION

I, **Tony Thomas** do here by declare that the dissertation titled **"Challenges and Coping Strategies of Children with Systemic Lupus Erythematosus (SLE)"** is based on the original work carried out by me and submitted to the University of Kerala during the year 2021-2023 towards partial fulfillment of the requirements for the **Master of Social Work** Degree Examination. It has not been submitted for the award of any degree, diploma, fellowship or other similar title of recognition before.

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ABSTRACT

Systemic Lupus Erythematosus (SLE) is a complex auto immune disease with diverse clinical manifestations affecting significantly the different organs of the body like brain, skin, heart, kidney etc. The studies show that it affects women, especially women of the reproductive ages, more frequently than men. The researches undertaken in the area indicate that the childhood onset SLE is much adverse than which is found among the adults, considering the disease activity. This study aims to explore into the lived experiences of the children living with SLE in order to identify the manifold challenges affecting the children and their coping strategies. The study adopts the qualitative design in order to gain an in depth understanding of the lived experiences of the children. Five participants receiving services from the hospitals in the different districts of Kerala were selected as the participants for the study.

The study brings to light the various challenges associated with childhood onset Systemic Lupus Erythematosus (cSLE). The commonly seen manifestations of SLE include fever, headache, joint pain, rashes, hair loss, fatigue etc. Since these symptoms mimic those of other common diseases, the caregivers fail to recognize the danger. This results in the delayed diagnosis. At times, the medical professionals also fail to provide the right diagnosis. The researches point out that the more the diagnosis gets delayed, the more severe the condition of the children is. In certain cases, there are episodes of seizures, paraplegia, loss of eyesight, bleeding etc. The condition gets worsened by the side effects of the medication. The various challenges have a detrimental effect on the ability of the children to perform the Activities of Daily Living (ADL). The psychological challenges affected by the children include fear of death, loneliness, lack of concentration, loss of self-esteem due to changes in the bodily stature, episodes of hallucinations, suicidal ideations. The loss of esteem affects the interaction of the children with the society. Hence the children are found with pessimistic approach towards the society. The economic costs attached with SLE is most often unbearable for the caregivers as well as the children. The study also brings to light the various coping strategies used by the children.

Key Terms: **Systemic Lupus Erythematosus, Diagnosis, Challenges, Coping Strategies**

CHAPTER ONE: INTRODUCTION

Chapter One: Introduction

1.1 Overview of the Chapter

This chapter functions as a prelude to the subject under study. The chapter encompasses the detailing of the background for the study, statement of the research problem and the significance for the study. Towards the end, the chapter provides the overall structure of the research wherein the contents of each chapter are briefed.

In the background of the study, the context for the research is detailed. It discusses the general notions surrounding the research topic, Lupus, etiology, prevalence, classifications, its historical and recent developments and various other implications of the disease conditions. The section will then move to discuss Systemic Lupus Erythematosus (SLE), childhood onset Systemic Lupus Erythematosus (cSLE). In the statement of the problem, the research gap is identified and presented systematically after delineating all the aspects of SLE relevant to the study. For the development of the problem statement, lots of literatures were reviewed. After stating the problem, the scope, relevance and the significance of the study is clearly mentioned. Lastly, the chapter includes a chapterization section, outlining the structure of the entire research. It provides an overview for the reader, giving an idea of what each chapter will cover.

1.2 Statement of the Problem

Systemic Lupus Erythematosus is a disease with thousand faces, having varying manifestations and presenting features. It is a condition when the body attacks its own cells and healthy tissues and can affect the different organs of the body like heart, kidneys, skin, brain and can be leading to mortality. The probability of mortality is quite higher in the SLE patients than in the general cohort. What makes SLE complicated is the presence of renal, cardiovascular disease and infection. As per the statistics, the disease is highly prevalent in the women of the reproductive ages. A person with SLE may experience different episodes of flares and remissions and the flares are when the disease is active.

Symptoms may vary from person to person. The initial presentation of SLE often mimics any other common disease. Due to this, the diagnosis may get delayed. The common symptoms like weight loss, fatigue, headache and low-grade fever are

accompanied by arthritis. The persons with SLE face arthritis related issues like stiffness and swelling on joints. Very often, people seek medical treatment when they are faced with the musculoskeletal manifestations of SLE. When the pain on the joints as well as the wrists become severe, treatment is sought out. In 75% to 85% of the patients, there are cutaneous manifestations. The butterfly rashes that may last for days to weeks, which can be also painful is a characteristic feature of SLE. Other features are the photosensitivity, hair loss, rashes etc. The disease condition has a negative impact on the work ability and Activities of Daily Living (ADL).

Among the listed symptoms, the fatigue poses severe threat. The studies reveal that the 67% to 90% of the patients experience fatigue. It is one which bothers the individuals, leading to a poor Health Related Quality of Life (HRQL) and employment disability. It often involves the psychological factors as well. Fatigue also leads to irritability, inability to concentrate, poor motivation. It has repercussions on the both the physical and mental life of the people living with SLE. It has a negative impact on the emotions, cognition, work, activities of daily living, leisure activities, social activities and family activities etc. The patients have to go through sadness or loss of motivation as a result of the disease condition. Few people also develop high depression, anxiety and suicidal ideations. The people also experience, coping disabilities, and abnormal illness related behaviour. (Kawka, 2021).

The researches undertaken in the area found that sleep disorders are associated with the disease condition. This also has links with steroids. The patients also have issues with body image since obesity is one among the features of SLE. Changes in the perceptions of the body image are overlooked by the researchers (Rodrigues, 2021). Negative body image also increases vulnerability to emotional distress, anxiety and depression. Intimacy is also affected when people feel shame about their bodies. A 2015 Journal of Immunology Research study found that impaired body image causes sexual problems (Delzell, 2015).

Another factor which complicates the scenario is the delayed diagnosis. Despite of the physician's increased awareness and medical advancements, the interval between the initial symptoms and the diagnosis is very long. The studies associate delayed diagnosis with worse outcomes (Kernder, 2021). The patients report that it takes five or six consultations on an average with different doctors before a diagnosis would be finally

made. SLE's effect on the quality of life, mental stability and other issues such as fatigue can depend on early diagnosis and treatment (Dollear, 2021).

The disease condition significantly affects the attempts of the people living with SLE to maintain their normal social interactions. The association between a negative attitude towards society and disease activity is discussed by various studies. Some patients have difficulties in communicating with the external world about their disease conditions. Sensitivity, excessive concern for privacy and an attitude that prioritizes self-protection clearly fortified the boundaries around the patients' social interactions (Huangfu, 2020).

The SLE has adverse outcomes on the academic achievement in the children with SLE and work place quality in the adults. This constitutes the indirect costs of SLE. The studies prove that the school attendance was severely compromised. Many studies report that the choice of education and vocation is affected by the disease. For adults, the disease prevents them from continuing their job. Their work productivity was also affected (Groot, 2021).

A 2016 study published in Nature Reviews Rheumatology found that the average annual direct health care costs of a person with lupus was $33,223. The study also determined that the average annual productivity cost (lost hours of economic productivity due to lupus) was between $1,252 and $20,046. The average annual total costs for people with lupus (combining direct and indirect costs) can be as high as $50,000. These estimates may be higher among people with lupus nephritis and more severe or active lupus.

The research studies state that the coping strategies used by the people with SLE vary. In many cases, the coping strategies used by the patients are not healthy enough to manage the challenges. From the available studies, few strategies that better combat challenges are identified. They are strong patient-provider relationship, optimism, peer relationship, social support etc. It has been found that adaptive coping strategies enhance the quality of life in the people living with SLE. A study indicated that avoidant or passive coping methods (avoidance, self-blame, and wishful thinking) were connected with unfavourable health effects, and passive forms of coping were associated with poor psychosocial adjustment to SLE (Córdoba, 2015).

The existing literature reveals that numerous studies have investigated Systemic Lupus Erythematosus (SLE), its challenges, and its correlation with various factors such as age, gender, race, colour, and socioeconomic status (SES). While the majority of these studies originate from Western countries, they highlight the physical, psychological, economic, and social difficulties associated with SLE. The review underscores that SLE is a multifaceted disease that affects the body's healthy tissues and organs. Delayed diagnosis of the condition exacerbates its complications. Consistently, all the studies emphasize that SLE has an adverse impact on the individual's health-related quality of life. The majority of the studies shed light on the detrimental effects of childhood-onset SLE on all aspects of patients' lives. The literature describes the various symptoms that may accompany SLE. The complications of the drugs and medication is clearly pointed out by few literature studies. Abundant studies identify the psychological effects of SLE, which consists of depression, mood disorders, suicidal ideations, lack of self-esteem. There are also many literatures that throw light into the treatment costs, both direct and intangible. The researcher has found that the vast amount of literature on SLE is based on Western context and most of them quantitative. Also, there is dearth of studies on the childhood onset Systemic Lupus Erythematosus (cSLE). The purpose of this study is to understand the challenges faced by the children with SLE and identify the coping strategies.

1.3 Background of the Study

Systemic Lupus Erythematosus is an auto immune disease, causing serious organ complications and death. Due to the diversity in the symptoms in the individuals, it is commonly called as the disease with a thousand faces. A life with Systemic Lupus Erythematosus is a complicated journey considering its impacts on the activities of daily living, physical, psychological and social health. Although SLE is mostly reported in the adults, its prevalence is seen in the children too with devastating complications. Very often, the diagnosis gets delayed due to the failure from the part of the caregivers and the healthcare professionals to duly recognize the causes of the symptoms. The symptoms of SLE which include headache, fever, rashes on the skin, joint pain etc mimic the symptoms of other common diseases resulting in the delayed diagnosis. The more the diagnosis gets delayed, the more severity the disease condition acquires. The concomitants of SLE are severe joint pain, swelling, headache, rashes, mouth ulcers,

fatigue, obesity as a result of medication. Apart from this, the children with SLE undergo psychological challenges like wrong perception of body, depressive episodes, hallucinations, anger issues, suicidal ideation etc. From a social perspective, the children with SLE have difficulties in the interaction with the friends and the society. The disease condition has adverse impact on the economic condition of the family, academic outcomes of the children and the workplace quality of the caregivers.

1.3.1 Lupus

The International Classification of Disease (ICD 10) defines Lupus as chronic inflammatory connective tissue disease marked by skin rashes, joint pain and swelling, inflammation of the kidneys as well as other problems. The symptoms exhibited by people with lupus are not always the same (WHO, 1994). It is estimated that at least five million people around the world have a form of Lupus. In India, the prevalence of SLE ranges from 14 to 60 per 100000 (Malaviya, 1997). Even though the prevalence is reported to be low, the studies in the area are scarce. Although men, children and teenagers form lupus, the studies show that lupus strikes mostly women of childbearing age (15-44). Women comprise the majority of the people living with SLE. (Estel, 2010). As per the recent studies, nine out of 10 adults with Lupus are women. The studies state that 10-15 percent of people with lupus will die prematurely due to the complications of the disease. As there are improved medications and treatment available, most people with lupus live on having a normal life span. In the life course of a person with lupus, there will be instances of both flares (periods of illness) and remission (periods of wellness). Lupus ranges from mild to severe.

1.3.2 History of Lupus

Since the Middle Ages, the term lupus (Latin for wolf) has been used interchangeably to describe a variety of disorders characterised by ulcerous scars, most commonly in the lower limbs. In the middle of the eighteenth century, French dermatologist Pierre Louis Alphée Cazenave provided a comprehensive clinical description of the disease, coining the term "lupus erythematosus" due to the characteristic rash resembling a wolf bite. However, it was only in the later period that the systemic nature of the disease was fully understood. The fundamental turning point in the history of lupus occurred at the beginning of the nineteenth century, when the distinction between cutaneous lupus and lupus vulgaris arose gradually. Following major contributions from Kaposi, Sequiera

and Balean, and Osler, the disease's systemic nature was recognised. The beginning of the twenty-first century is now marked by an in-depth understanding of the disease's aetiology and the appearance of biologic and targeted treatments, paving the way for better lupus patient care (Felten, 2022).

1.3.3 Classification of Lupus

Lupus is of different types. The major forms of Lupus are listed below:

Systemic Lupus Erythematosus: The seventy percent of the people with Lupus have Systemic Lupus Erythematosus (SLE). In SLE, A major organ or tissue in the body, such as the heart, lungs, kidneys, or brain, will be impacted in almost half of these cases (Bartel, 2022).

Cutaneous Lupus: It accounts for ten percent of all the lupus cases. It is called so because it affects skin. It leads to red, thick, and often scaly rashes and sores that may burn or itch. The condition is not life threatening nor contagious (Lee, 2013).

Drug-induced lupus: The ten percent of lupus that is seen in the world is drug-induced lupus. It is caused as a result of the high doses of certain medications. The symptoms can be subsided by discontinuing those medications (Bartel, 2022).

Neonatal Lupus: This condition is caused as a result of the impact of mother’s antibodies on the foetus. The baby develops symptoms like skin rash, liver problems or low blood cell counts.

1.3.4 Prevalence of Lupus

The estimated incidence, prevalence, and death rates of systemic lupus erythematosus (SLE) differ significantly among geographic locations. Differences in ethnicity, environmental exposures, and socioeconomic position are factors that contribute to regional heterogeneity. Certain ethnic groups are more vulnerable to develop SLE and increased morbidity and mortality (Barber, 2021). Certain research studies point out that the severity of SLE varies according to the racial disparities. The prevalence of SLE is higher than others in black female persons. One among the 537 black female persons is an SLE patient (Somers, 2014). It outlines that women from racial and ethnic minority groups tend to develop lupus at a younger age, experience more serious complications and have higher mortality rates. The prevalence of SLE varies between

different sex and age groups. SLE is found more frequently in high income countries. SLE is found to be less prevalent among those with white ethnicity (Rees, 2017). A recent study, "Environmental and Atmospheric Factors in Systemic Lupus Erythematosus: A Regression Analysis" undertaken by Frank Curriero et al explains that flares in lupus are associated with increase or decrease in temperature (Stojan, 2019).

1.3.5 Etiology

There are varied opinions among the researchers about the causes of lupus. The primary cause attributed by the researchers is the association between genes and lupus. According to some scholars, the risk for development of lupus in siblings of individuals with the disease is about twenty times higher than the general population. Researchers associate more than 50 genes with SLE. Certain ethnic groupings (those of African, Asian, Hispanic/Latino, Native American, Native Hawaiian, or Pacific Island heritage) are at a higher risk of having lupus, which may be due to shared genes. On the other hand, there are some scholars who argue that the environmental factors are the triggering causes of the disease. The triggers for SLE found in the environment include UV rays from the sun and fluorescent light bulbs, drugs, infection, colds or viral illness, exhaustion, emotional stress etc. There is a debate between the two positions going on currently. A few scholars opine that sex hormones explain the increased prevalence of SLE in women. Estrogen hormone generated by women is an immunoenhancing hormone. Women have a stronger immune system than that of men and the probability of autoimmune diseases is much higher in women than in men (Causes of Lupus, 2019). Women exhibit lupus symptoms during menstrual periods and during the pregnancy. At this time, the production of Estrogen is generally high. However, the researches proving the association between the lupus in women and Estrogen are scarce.

1.3.6 Symptoms of Lupus

The symptoms of lupus vary from person to person. There is no uniformity in the pattern of the synonyms. Symptoms may change overtime. The severity of the disease can range between mild and extreme. Few of the symptoms are arthritis, fever, fatigue, rashes on the skin, sensitivity to the sun, hair loss, painless sores, change of colour in the fingers and toes, swelling on the legs or around the eyes, headaches, dizziness, depression, confusion, seizures, abdominal pain, heart problems, low blood cell counts

etc (Branch, 2023). Fatigue is a primary symptom for approximately 50%-90% of persons with lupus. Lupus-related fatigue appears to be caused by a variety of causes, including disease activity, anxiety disorders, sleep abnormalities, vitamin D deficiency, and a lack of exercise.

Fatigue can have a substantial impact on a patient's quality of life, including the capacity to perform at home and at work (Lupus Symptoms, 2021).

Approximately half of persons with lupus have a distinctive red "malar" rash or colour change that appears over the cheeks and bridge of the nose in the shape of a butterfly. The rash may persist for days or weeks and can be uncomfortable or itchy. Rashes can appear on the face and ears, upper arms, shoulders, chest, hands, and other sun-exposed areas. Because many persons with lupus are photosensitive (sensitive to sunlight), skin rashes frequently develop or worsen after being out in the sun. Some individuals believe that the presence of the butterfly rash indicates the onset of an illness (Lupus Symptoms, 2021).

Arthritis, defined as inflammation or swelling of the joint lining, affects up to 90% of persons with lupus. The most frequent arthritis symptoms are stiffness and pain, most commonly in the hands and wrists. Arthritis symptoms can come and go and migrate from one joint to another. Pain and stiffness are typically worse in the morning and improve throughout the day (Lupus Symptoms, 2021).

Flares are episodes in which the symptoms worsen and people get ill. Flares can appear and disappear. People can experience swelling and rashes one week and then have no symptoms the next. Sometimes flares occur without obvious symptoms and are detected only through scientific tests. Some flares are minor, while others are severe and necessitate medical attention. Disease flares frequently occur without apparent cause, maybe due to a cumulative buildup of autoimmunity. There is evidence, however, that certain factors in the environment may cause the condition. These include UV radiation exposure, viruses, certain hormones, and medicines, all of which can stimulate the innate and adaptive immune systems, causing inflammation, cell death, and clinical symptoms. Disease flare-ups, as well as their treatment, particularly with glucocorticoids, can cause severe organ damage (Fernandez, 2016).

Cardiovascular disease, renal disease, and stroke are the most major health hazards or the potential complications. Lupus nephritis occurs when the disease affects the kidneys, and patients typically require intense pharmacological treatment to avoid lasting damage. Lupus can also target the brain or central nervous system, resulting in convulsions or stroke.

1.3.7 Diagnosis and treatment

Lupus diagnosis might be difficult. There is no single test that can provide doctors with a definitive "yes" or "no" answer. It can take months, if not years, to obtain all of the necessary information.

Making a lupus diagnosis is similar to assembling a puzzle. The doctor will consider numerous puzzle pieces, including the symptoms, medical history, family history, and lab testing. An individual may be diagnosed with lupus if enough of the puzzle pieces come together. However, the doctors rely mostly on the laboratory test to make the final conclusion. The test usually undertaken include routine blood tests, urine test, biopsies, Antinuclear Antibodies Test (ANA) etc. Treatment of Lupus is a team effort. Doctors who are specialized in various fields may have to come together to treat lupus. Usually, the rheumatologists are the specialized doctors to develop the treatment plan for the people living with lupus. Though there is no complete cure for lupus, the treatment can help in controlling the symptoms, preventing the immune system from attacking the body and protecting the organs from the damage (Diagnosing lupus, 2021).

There are various medicines used to treat the disease conditions and the type of medicines depend upon the type of symptoms. The most common type of medicines used to treat lupus include anticoagulants (to help prevent blood clots), anti-inflammatories, antimalarials (to protect skin from rashes and UV light), biologics (to help the immune system work properly), immunosuppressives (to help keep the immune system from attacking the body), steroids (to help with inflammation) etc. It is an undeniable fact that the medication would cause serious side effects. Certain medications would have an adverse effect on women who are either pregnant or breastfeeding.

1.3.8 Systemic Lupus Erythematosus

SLE (systemic lupus erythematosus) is the most frequent form of lupus. SLE is an autoimmune disease in which the immune system attacks its own tissues, resulting in extensive inflammation and tissue destruction in the organs involved. It has the potential to harm the joints, skin, brain, lungs, kidneys, and blood vessels. Lupus has no cure, although medical treatments and lifestyle adjustments can help control it. SLE typically begins in females during their reproductive years, while it can occur at any age. African Americans and Asians are disproportionately affected by the disease. It is more common among African American women and other ethnic minority women. SLE affects 20% of persons while they are children or teenagers. Lupus that begins in childhood is known as childhood-onset SLE, or cSLE (Monga, 2022). SLE can range in severity from mild to life-threatening. A doctor or a team of experts who specialise in the care of SLE patients should treat the disease. People with lupus who receive good medical care, preventive care, and education can improve their function and quality of life dramatically. SLE patients may have a variety of symptoms such as fatigue, skin rashes, fevers, and joint discomfort or swelling. Sun sensitivity, mouth ulcers, arthritis, lung issues, heart problems, renal problems, seizures, psychosis, and blood cell and immunological abnormalities are all possible symptoms. Some individuals may experience flares of SLE symptoms every so often, perhaps even years apart, and then go into remission at other times. Other individuals, on the other hand, may experience SLE flares more regularly throughout their lives. SLE can have both immediate and long-term consequences in a person's life. Early detection and treatment can help lessen the harmful consequences of SLE and improve the chances of having improved function and quality of life. Poor access to care, delayed diagnosis, ineffective therapies, and poor adherence to therapy regimens may exacerbate the harmful consequences of SLE, resulting in additional complications and a higher risk of death (Dall'Era, 2013).

While an early diagnosis improves a person's quality of life and results, acquiring a SLE diagnosis can be a tough and time-consuming process. Lupus is known as the "great imitator" because its early signs and symptoms might be similar to those of other diseases. The longer it takes to diagnose, the more disease activity there is, the more illness-related damage and weariness there is, and the lower the health-related quality of life. Reducing this delay may enable monitoring and treatment at an earlier stage before severe organ involvement might have occurred.

The leading causes of mortality for people with SLE are heart disease, malignancy and infection. The other factors that may contribute to the mortality rate of SLE include disease duration, high disease severity at diagnosis, race/ethnicity, male sex, low socioeconomic status, poor patient adherence, inadequate patient support system and limited patient education.

SLE has the potential to impair a person's physical, mental, and social functioning. These constraints that persons with SLE face might have an influence on their quality of life, especially if they are fatigued. Fatigue is the most common symptom that has a detrimental impact on persons with SLE's quality of life (Jolly, 2010).

Because employment is crucial to a person's life, many studies use it to determine the quality of life of people with SLE. According to certain research, the longer a person has SLE, the less likely they are to be employed. Only 46% of patients with SLE who are of working age report being employed (Robinson, 2010).

Treatment regimen adherence is frequently a difficulty, particularly among young women of reproductive age (15 to 44 years). Because SLE treatment may need the use of powerful immunosuppressive drugs with substantial side effects, female patients must discontinue the medication before and throughout pregnancy to safeguard their unborn offspring (Systemic lupus erythematosus (SLE), 2023).

1.3.9 SLE in children

SLE is the "disease of a thousand faces." When lupus commences in an individual less than 18 years of age, it is commonly referred to as Childhood-onset Systemic Lupus Erythematosus (cSLE). It causes considerable damage and disability in children. Although the childhood onset SLE is similar to that of aSLE (adulthood onset Systemic Lupus Erythematosus), however there are notable variances in the frequency and severity of specific clinical signs. Patients have higher disease activity, damage, and require more intensive treatments when compared to those with disease beginning in adulthood (Charras, 2021). According to data from Canada, there is a higher prevalence of neurological and renal involvement at the time of diagnosis among children with SLE versus adults with SLE. In the case of cSLE, the female to male ratio is 4:3, but in the case of Adulthood Systemic Lupus Erythematosus(aSLE), the ratio is 9:1. aSLE is approximately ten times more prevalent than cSLE. It has been found that

cSLE uses more steroids and immunosuppressive drugs then aSLE (Mina, 2013). The treatment costs of cSLE surpass aSLE.

Childhood-onset systemic lupus erythematosus is an uncommon disease that is more common in Southeast Asian children than in Western children. Although the exact cause of SLE is still unknown, genetic, hormonal, immunologic, and environmental variables are thought to be contributors. It is distinguished by a pubertal onset and a female predominance. The most common symptoms are fever, malar rash, and skin inflammation. The disease activity is high among the children and the organ damage occurs early and continues to accumulate over the time.

1.4 Significance of the Study

Systemic Lupus Erythematosus is a disease with thousand faces, with varying manifestations and presentations. Its severity depends on the impacts it exerts on the different organs. It causes death when the people living with SLE develop renal or cardiovascular manifestations attached with SLE. The numerous studies have already outlined the adverse outcomes of the adulthood onset SLE. The studies underscore that the childhood onset SLE is much worse than the SLE found in adults since it can cause organ damages and increased frequency of flares. The various challenges faced by the children living with SLE is heartbreaking. The studies that delve into the lived experiences of the children living with SLE in India is scarcely found. This study aims to explore into the lived experiences of the children with SLE in order to understand their various challenges and coping strategies.

The challenges associated with SLE causes severe troubles for the children since it affects their mobility, Activities of Daily Living (ADL), energy level, body image, peer friendship, social support etc. The children also have to go through emotional risks and other psychological challenges. This may include depression, anxiety, suicidal ideations, loss of motivation etc. Apart from this, the disease leads to a pessimistic attitude towards the society. In addition to this, the direct and the indirect costs associated with SLE is beyond calculations. The disease has worse outcomes on the children as well as the caregivers. Along with identifying the unique challenges and the coping strategies, the study aims to understand the less adaptive coping strategies and the existing gaps in the welfare and well-being of the children.

The study also aims to find out the diverse needs of the children based on data collection and data analysis. This would help the social workers to plan and develop intervention plans for the holistic well-being of the children.

1.5 Chapterization

The research is divided into seven chapters. The chapterization of the research dissertation is as follows:

Chapter I: Introduction

An introduction to the study is provided in the first chapter. It includes the various concepts related to the study and states the problem addressed as a research paper, its intensity and later it explains the need and relevance of the study in the present scenario.

Chapter II: Review of literature

This chapter deals with a review of literature that analyses various studies conducted on this topic from different perspectives. This helps the researcher to identify the dimension in which the researcher needs to focus more. A gap in these studies gets discussed in the following.

Chapter III: Research Methodology

It discusses the methodology that the researcher uses in his study. It includes the details like title, research questions, research design, sampling techniques, details of the pilot study, Method of data collection, data analysis, and limitations of the study.

Chapter IV: Case Description

Details of cases used in the study are recorded in this chapter in an elaborated manner for a better understanding of each case. Cases of respondents are described through narrative and verbatim reporting.

Chapter V: Thematic Analysis and Discussion

Thematic analysis, discussion of the case, analysis to link the findings back to existing literature, and discussion of the data collected for the study are discussed in this chapter in a detailed manner.

Chapter VI: Findings, Suggestions and Conclusions

This chapter deals with major findings followed by discussions, suggestions, and conclusions. The last pages of the dissertation will include the bibliography, appendix, and tools used for data collection in this study.

1.6 Summary of the Chapter

This chapter presents an overall picture of the topic. The chapter follows a progressive pattern, flowing from the general to the particular aspects about the research topic. Through a systematic review of the literature, the gap is identified and the research problem is explained. The chapter also elaborates on the significance of the study by detailing its scope and explaining how the present study contributes to the existing knowledge. Lastly, the chapter provides a detailed outline of the research structure, giving an overview of the study's framework.

CHAPTER TWO: LITERATURE REVIEW

Chapter Two: Literature Review

Literature review holds a significant place in the development of research question, themes and research gap. “Your task is to build an argument, not a library.” (Rudestam, 2007).

2.1 Overview of the Chapter

There is a vast amount of knowledge, almost on all topics, around us. It is the task of the researcher to explore into the reservoir of knowledge and identify the credible and authentic ones to build her/his argument. A literature review throws light on the academic literature available on a specific topic, the authors, existing theories, relevant questions pertaining to the subject matter and methods and methodologies that are useful. A well-prepared literature review will help us know what research has already been done and identify what is unknown within the topic.

In this chapter, the relevant studies carried out in the area of Systemic Lupus Erythematosus (SLE) are reviewed and the key takeaways are pointed out. The literatures that speak of the physical, psychological and social challenges of SLE are taken into consideration. For the fulfillment of the purpose, the literature review is arranged thematically. Towards the end of the chapter, all the studies are evaluated in order to identify the gaps in the literature.

2.2 Review of Literature

2.2.1 Studies on Systemic Lupus Erythematosus (SLE)

“Systemic Lupus Erythematosus(SLE) is a chronic, relapsing, inflammatory, and often febrile multisystemic disorder of connective tissue, characterized principally by involvement of the skin, joints, kidneys, and serosal membranes; it is of unknown etiology, but is thought to represent a failure of the regulatory mechanisms of the autoimmune system; the disease is marked by a wide range of system dysfunctions, an elevated erythrocyte sedimentation rate, and the formation of LE cells in the blood or bone marrow.” (WHO, 1994).

The book written by Giffords (2003) sheds light on the general features of Systemic Lupus Erythematosus (SLE) primarily affects females. Although nine out of ten lupus

patients are women, men do occasionally develop the disease. While Lupus can afflict people of any ethnicity, but women of colour, including African Americans, Latinas, Asians, and Native Americans, are two to three times more likely to get the disease. In the case of lupus, the body produces antibodies that, in opposition to their normal protective role, attack the body's healthy tissues and organs. Skin, joints, kidney, heart, lungs, neurological system, blood, and other organs or systems may be impacted by lupus. It is neither contagious nor malignant. Estimates place the disease's average age of onset between 15 and 44, and its estimated number of victims at 500,000. Many autoimmune disease sufferers are unable to identify the exact year they first fell ill. The search for a diagnosis can be tedious, stressful, and frightening for people with lupus. Most people have symptoms for years before being diagnosed. In reality, it's very unusual for patients to say that during the initial stages of their illness, medical personnel were sceptical of them while they sought a diagnosis. In addition, many people encounter opposition from family, friends, or other people. A person may get perplexed or doubt themselves as a result. There could be instances even after despite a comprehensive examination and a variety of tests, a patient's doctor may not be able to provide a definitive diagnosis.

The review by Pons-Estel G et al. (2010) focuses on the burden and patterns of disease in systemic lupus erythematosus (SLE), as well as the impact and interplay of gender, ethnicity, age, and psychological factors with relation to disease development. African Americans in the United States are definitely at a higher risk when it comes to women of reproductive age. In contrast, a distinct trend is typically observed in other groups, with women over 40 having the highest age-specific incidence rates. In non-white communities around the world, the disease is 2 to 4 times more common and more severe, and it tends to be more severe in men, as well as in paediatric and late-onset lupus. Patients with SLE currently have a 5-year survival rate of more than 90%. Socioeconomic position may be more of a determinant in ethnic minorities' poorer survival outcomes than ethnicity itself, and good social support has been found to be a protective factor for SLE patients as a whole. Disagreements between the doctors and the patient may affect the quality of care.

The article of Carter et al. (2016) outlines the specific features of SLE. A multisystem autoimmune disorder called Systemic Lupus Erythematosus (SLE) has the potential to cause fatal organ consequences. The full extent of its worldwide burden, including its

incidence and prevalence, disparate effects on communities, financial expenses, and ability to degrade health-related quality of life, is still unknown. The reported incidence and prevalence of SLE varies widely across the globe. Despite the disease's heterogeneity, distinct patterns of the disease's presentation, severity, and course are frequently linked to variations in racial or ethnic background, level of education, health insurance status, degree of social support, adherence to medication, as well as environmental and occupational factors. Given the disease's potential to inflict such severe and broad organ damage, not only are the associated direct costs substantial, but these costs are occasionally surpassed by indirect expenses due to lost productivity in the workplace. It should come as no surprise that individuals with SLE are likely to experience significantly lower health-related quality of life as an intangible cost.

The article of Malaviya et al. (1997) outlines the status of SLE in India. Since the opening of a clinical immunology lab at a significant educational institution in New Delhi in 1968, SLE has received much research and reporting. From the middle of 1980 onward, a number of additional centres in various parts of India, including Chennai (formerly known as Madras), Mumbai (previously known as Bombay), Calcutta, and Hyderabad, published their local experiences on SLE. Similar rates of arthritis, dermatitis, photosensitivity, seizures, and psychosis were seen as in other racial groups. The range of positivity for ANA and anti-DNA antibodies was similar to that observed in other racial groups. Alopecia, renal lupus, mouth ulcers, and neurological involvement were reported at increased proportions when compared to other series, reaching statistically significant values in comparison to select racial groups. According to European statistics, patients from India had significantly lower 5- and 10-year survival rates. This could be related to the country's general public health situation, such as inadequate hospital management facilities, delays in diagnosis due to a lack of awareness of the disease, referral bias in which only serious patients reach major city hospitals, or a truly severe disease among Indians, or a combination of these genetic, environmental, and/or sociocultural factors.

2.2.2 Biophysical challenges of SLE

In Medline Plus, which is the online magazine of the United States National Library of Medicine, Gonter (2023) describes SLE as a condition which may vary among the affected individuals, and can involve many organs and systems, including the skin,

joints, kidneys, lungs, central nervous system, and blood forming system. SLE is one among the auto immune disorders that mistakenly attacks the body's own tissues and organs. SLE manifests in the individuals in various forms: There is extreme tiredness (fatigue), discomfort or illness, fever, loss of appetite, weight loss. Individuals also may develop joint pain, muscle pain and weakness. Skin problems pose threat to individuals with SLE. SLE is commonly known for its butterfly rashes, a flat red rash across the cheeks and the bridge of the nose. Skin problems get worsened when exposed to sunlight. People with SLE have episodes in which the condition gets worse (exacerbations) and other times when it gets better (remissions).

In the study on the impact of SLE on the ADL, Keramiotou et al. (2021) were trying to examine hand function and performance in activities of daily living (ADL) in patients with SLE. ADL performance and hand function (grip strength, pinch strength, and dexterity) were assessed in 240 SLE patients and 122 healthy controls with similar ages and biological sexes. The Jamar Dynamometer, pinch gauge, and Purdue Pegboard Test were used, respectively, to measure grip strength, pinch strength, and dexterity. Disabilities of the arm, shoulder, and hand (DASH) and HAQ were used to evaluate self-reported ADL performance. Analysis using regression was done to determine the causes of hand dysfunction. In patients with SLE, hand involvement is one of the major contributors to reduced function in daily living activities (ADLs), home chores, productivity and absenteeism, and health-related quality of life. In the total SLE cohort and the subset of patients achieving lupus low disease activity status compared with healthy subjects, all hand function and ADL performance indicators were significantly worsened. Joint pain, often underestimated in SLE, was the major determinant of hand function and ADL performance. Hand function and performance of daily activities are significantly impaired in SLE, even in patients who achieve LLDAS, suggesting the need for their evaluation and management in clinical practice.

The article by Olesińska & Saletra (2018) points out the physical, psychological and social aspects of SLE. Studies prove that the quality of life in patients with SLE is lower than in general population. Individuals with SLE have a quality of life that is equivalent to individuals with rheumatoid arthritis and Acquired Immune Deficiency Syndrome (AIDS). The two symptoms that patients most frequently identified as having an impact on their quality of life were fatigue and uneasiness. Constant fatigue has a terrible impact on a variety of facets of patients' lives and unquestionably lowers quality of life.

Constant fatigue is thought to be the most prevalent symptom of SLE in between 50 and 90% of patients. The unpredictability, dominance, and control of fatigue are described by patients. The most often mentioned causes of fatigue are disease activity, sleep issues, emotional disorders, pain, sadness, anxiety, despair, obesity, restricted physical activity, co-occurring diseases, vitamin D insufficiency, and SLE therapy. Studies on how disease activity and coexisting conditions affect the severity of fatigue have produced conflicting results. The majority of studies do not demonstrate that fatigue in SLE is solely due to the concomitant disorders. Fatigue restricts daily activities and frequently forces a patient to give up earlier interests in hobbies (like sports) or employment. Patients often experience helplessness, anger, and guilt. Nearly 95% of patients with SLE report sleep disorders, mainly waking up frequently and restless sleep. Patients with SLE who do not exercise enough are more likely to develop cardiovascular disease, osteoporosis, obesity, tiredness, and sleep difficulties. Joint pain, bleeding (caused by haematological issues), and an increased risk of fractures are all feared. The patients' photosensitivity makes it impossible for them to engage in outdoor sports. Contrarily, their obesity deters them from participating in sports. Because of their despair and lack of interest, the patients stop exercising.

In a study on the life course changes brought by SLE, Huangfu (2020) examines patients with SLE as a means to explore the impacts of chronic disease on life courses. Semi-structured in-depth interviews were conducted with nine patients in China in 2017; participants were included based on their having or having had facial butterfly erythema. Skin rashes, uneven pigmentation, vitiligo, scars, loss of teeth, alopecia, facial hair, stretch marks, weight gain, exhaustion, pain, despair, unpredictable flare-ups, and a loss of independence are typical clinical signs of the illness. The facial erythema, pigmentation, light sensitivity, hair loss, skin ulcers, and pain in the muscle fibres will be present in about two thirds of SLE patients. Daily reminders of the illness may come in the form of physical symptoms like sun sensitivity, joint pain, weariness, and malaise. The problems with the body image have increased patients' social isolation and decreased communication. The bodily changes impacted their bodies and identities. They begin to view themselves as patients. They therefore felt obligated to devise means of concealing the disease's physical manifestation. In order to conceal their illnesses from others, participants used makeup and clothing to construct an alternate identity for themselves. Look like normal people was what they intended to achieve.

In the study on barriers in employment, Booth et al. (2018) were trying to understand the reasons for the workplace disability and unemployment of SLE affected people. The study found that SLE has detrimental effect on individual's ability to work. It leads to disability, absenteeism and increased levels of ill-health retirement. From the online survey of 121 people, it could be summarized that SLE has a considerable impact on patients' physical, social and economic well-being. In the introductory part of the study, the researchers refer to various studies. In cohort research of a population from the southeast of the United States, Drenkard et al. came to the conclusion that the risk of unemployment in SLE is more than the overall population by roughly fourfold. SLE has a significant negative impact on both individuals and society. They stated that fatigue had the greatest impact on Work Productivity Impairment (WPI) for those who were working. The severe burden of systemic lupus erythematosus on patients' productivity and careers was highlighted in Gordon et al.'s online survey of European lupus patients, which also revealed the influence of exhaustion on WPI. These significant studies quantified the severe impact of SLE on people's capacity to participate in the workforce. The researcher argues that loss of employment causes substantial distress to individuals, loss of individual income, and societal costs. SLE can last for decades and mostly affects young women, which could have a significant negative influence on a person's ability to pursue higher education, find employment, and advance personally. It may prevent someone from achieving educational milestones and from getting a job, which could have a detrimental impact on how they turn out in their working lives. People's physical and psychological health will suffer due to the resultant decline in quality of life, psychological status, and income from being unable to participate fully in the workforce. The study gest concluded by offering suggestions to accommodate people with SLE in the workplaces.

The literature review conducted by Schmeding and Schneider (2013) aims to evaluate the current knowledge of the burden of Systemic Lupus Erythematosus on individual patients, with a particular focus on Health Related Quality of Life (HRQoL), Activities of Daily Living (ADL), individual symptoms, such as fatigue and pain, work disability and employment. A Medline (PubMed) literature search was done, and all papers from January 2000 to May 2010, updated in June 2013, that dealt with the burden of SLE were qualitatively analysed. The current literature review showed that SLE significantly affects patients' HRQoL and capacity for doing everyday tasks, leading to a high

prevalence of impairment (25–57%). The HRQoL of patients with SLE is consistently poorer than that of matched healthy control individuals or the population norm, according to numerous studies, and the disease has an impact on all facets of HRQoL (including physical and mental health, energy, pain, and social and emotional functioning). The burden of the disease on patients is shown by the fact that HRQoL and disability appear to be worse in people with SLE than in those with other chronic diseases. The analysis shows that many patients with SLE perceive their health as being suboptimal, with 35–50% of patients rating their health as 'fair/not so good' or 'poor'. In addition, some patients report that they find it difficult to cope with their disease. These findings are reflected in the high prevalence of unmet needs (94–100%), relating primarily to physical, daily living and psychological concerns, reported by patients with SLE. The analysis also reveals that physician and patient assessments of disease activity and health status in SLE differ considerably. Data from studies of discordance between patients' and physicians' assessments suggest that there needs to be a greater emphasis on patients' psychological and physical well-being and less emphasis on clinical and laboratory measures. In terms of symptom load, individuals with SLE frequently experience fatigue, pain, sleep disturbances, and neuropsychiatric symptoms, including anxiety, depression, and cognitive impairment. There are regularly reports of other co-morbidities. The HRQoL of the patient is significantly impacted by all of these indications and symptoms. Fatigue, the most prevalent SLE-related complaint, seems to be connected not to disease activity or damage but rather to both poor sleep and depression.

In the study on the effects of fatigue and pain on ADL in Systemic Lupus Erythematosus, Ozel et al. (2015) studied the effects of pain and fatigue on daily life activities of Systemic Lupus Erythematosus patients. The study sample included 74 SLE patients who were presented to outpatient departments of a university hospital and two local hospitals between 30.9.2009 and 15.5.2010. Data was collected using the Fatigue Severity Scale, Katz's Activity's Daily Living Index, Lawton and Brody's Instrumental Activities of Daily Living, and the McGill Pain Questionnaire. The study of the symptoms showed that 89.1% were determined to have butterfly rash, 86.5% photosensitivity, 17.6% oral ulcers, 91.8% arthritis, 4.0% serositis, 18.9% renal disorders, 9.4% neurological disorders, 6.8% hematologic disorders, 8.1% immunologic disorders, 25.7% fever, 90.5% fatigue, 32.4% anorexia, 8.1% hair loss

(alopecia), 18.9% weight loss, 78.4% ANA positivity and 99.5% pain. When the patients who took part in the study were asked how much the disease affected their social and professional lives, 66.2% replied that it did, 32.4% said that it did so slightly, and 1.4% indicated that it had no impact. It was discovered that the symptoms of SLE caused patients to experience ongoing or recurrent deficiencies that prevented them from performing their daily activities, that SLE significantly affected their work lives, that this effect increased when SLE was coupled with neuropsychiatric issues, and that the symptoms of SLE negatively impacted their social relationships and sexual lives.

In the study on the psychosocial dimensions of SLE, Beckerman et al. (2011) were trying to examine the psychosocial challenges faced by those living with SLE and to identify the sociodemographic factors that have an impact on the lives of people with Systemic Lupus Erythematosus. The study was conducted on 378 patients diagnosed with SLE and receiving services from SLE Lupus Foundation in New York City. Changes in appearance brought on by SLE and physical restrictions brought on by SLE (mainly owing to pain in the muscles and joints) were the most common overall causes of self-reported depression and anxious sentiments. Weight gain and hair loss were the most likely medication side effects and also the most likely causes of SLE-related depression and anxiety.

In the study on the Health-Related Quality of Life, Fatigue and Mood in Patients with SLE, Waldheim et al. (2013) tried to investigate Health-Related Quality of Life (HRQoL), fatigue, anxiety and depression in patients with systemic lupus erythematosus (SLE) and higher levels of pain and to compare them to patients with lower levels of pain and controls. Questionnaires pertaining to self-reported pain, HRQoL, exhaustion, anxiety, and depression were given to the participants. Additionally, medical evaluations were documented. In comparison to patients with lower levels of pain who did not substantially vary from the general population in most categories, those with SLE who scored higher degrees of pain were more fatigued, anxious, and depressed and had poorer levels of HRQoL. These findings highlight the need of identifying individuals who are experiencing higher levels of pain and who may require more intensive multimodal therapies to lessen symptom load.

The study conducted by Pattersson et al. (2012) were trying to explore the difficult symptoms of SLE and determine how these symptoms are related to HRQoL. As part

of this study, the written responses from 324 SLE patients were collected and the responses were categorized. There were found to be 23 different groups of symptoms. Fatigue (51%), pain (50%), and musculoskeletal distress (46%) were most frequently reported. Patients reporting fatigue showed a statistically significant impact on both mental and physical components of HRQoL.

The study led by Sutcliffe (1999) aims to determine the health status of patients with systemic lupus erythematosus and to identify the associations of this domain. At two centres, a study was conducted on 155 SLE patients who had been seen regularly. Compared to a control group, patients with SLE exhibited significantly lower SF-36 ratings on each subscale. Poorer physical role-physical function, bodily discomfort, overall health, vitality, and social role were all related to higher disease activity. Higher scores in physical function, bodily discomfort, overall health, vitality, social function, role-emotional health, and mental health were linked to greater social support. Physical function and overall health deteriorated as end organ damage increased. Better general health was related to higher patient general satisfaction with care.

The article by Hussain et al. (2022) brings out the effects of the diagnostic delays on the psychical and social aspects of children with SLE. Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease that affects numerous organ systems and has a wide range of clinical symptoms in its victims. Studies have found that patients with childhood-onset systemic lupus erythematosus (cSLE) have higher morbidity and mortality rates than patients with adult-onset SLE, despite recent improvements over the previous few decades. The interaction of several factors might result in diagnostic delays that worsen disease activity, damage multiple organs, raise the likelihood of hospitalisation, and require severe treatment. Additionally, despite recent developments in lupus treatment, prolonged illness duration in these young patients can have devastating psychosocial consequences and dramatically lower their quality of life (QOL), both in terms of their health and in general. Patient self-esteem, education, employment, healthcare use, and mental health are significant variables that are impacted.

The book authored by Giffords (2003) elaborates on the symptoms associated with SLE. Skin rashes, anaemia, renal involvement, difficulty when breathing, hair loss, sun sensitivity, and Rayaund's phenomenon are some additional prevalent lupus symptoms.

Each person experiences different symptoms. One reason lupus is challenging to diagnose is due to this. In the early stages of lupus, there are many vague symptoms. These are known by doctors as "nonspecific symptoms." Other ailments can also exhibit same symptoms. The Lupus Foundation of America claims that many lupus symptoms resemble those of other illnesses; they can be vague and frequently come and go, which makes it challenging to diagnose the condition. Lupus is typically diagnosed after carefully reviewing the patient's whole medical history, analysing the results of standard laboratory tests, and performing some special testing.

The book of Giffords (2003) gives the updated list of conditions that might suggest lupus. If four or more of the eleven abnormalities listed below are present at any given moment, a person is considered to have lupus.

1. Malar rash (butterfly): Rash on the cheeks or nose

2. A red, elevated rash called a discoid

4. Oral or Nasal Ulcers: Recurrent sores in the mouth or nose.

3. Photosensivity Sensitivity: Reaction to sunlight or ultraviolet A and B radiation.

5. Inflammation in two or more joints is a symptom of arthritis.

6. Serositis: An inflammation of the lung, heart, or stomach lining

7. Urine samples with excessive protein or unusual silt that may be observed under a microscope indicate kidney disease.

8. Neurologic Disorder: Psychosis and/or Seizures.

9. Hemolytic anaemia, low white blood cell counts, and low platelet counts.

10. Immunologic abnormalities: Blood tests showing antiphospholipid antibodies, lupus anticoagulant, anti-DNA, false-positive syphilis test, or a positive anti-SM are among the immunologic abnormalities.

11. Positive Antinuclear Antibody (ANA) test: Obtained via a blood test, a positive ANA suggests a rheumatic disease is likely.

2.2.3 Psychological challenges

The study led by Ji et al. (2012) tried to examine the connection between psychological distress and concerns about one's physical appearance in female adolescent SLE patients. In order to ascertain how these demographic and clinical factors were associated to the dependent variable psychological distress, a total of 84 female adolescents with SLE and 80 age-matched healthy adolescents had their degrees of appearance concern assessed. The severity of the illness was evaluated using the Systemic Lupus Erythematosus Disease Activity Index. The Children's Depression Inventory (CDI) was used to assess depression. The Self-Perception Profile for Children was used to gauge the degree of preoccupation with appearance. Comparing these patients to healthy controls of similar age and sex, the total CDI showed that they had higher depressive symptoms. Additionally, 32 (38.1%) of the patients had CDI scores greater than 19, indicating a comparatively higher risk of developing depression. In comparison to the SLE group, the CDI in the control group was considerably lower. Age and appearance concern were both significant predictors of depression in patients with SLE, and the former was substantially associated, according to correlation and multiple regression models. This suggests that in female adolescents with SLE, concerns about appearance may be linked to sadness. The findings imply that anxiety about one's looks is substantially linked to depression in female adolescents with SLE and should be frequently evaluated.

The article of Deborah et al. (2012) outlines the psychological as well as physical symptoms of SLE. There are 19 different neuropsychiatric lupus (NPSLE) symptoms associated with SLE, which can affect both the central and peripheral nervous systems. Up to 85% of individuals with cSLE who acquire NPSLE do so during the first two years of diagnosis, and up to 65% do so at any point during the course of the disease. Headache Symptoms ranging from mild to severe headaches that require prescription pain medication occur in 50 – 95% of patients. In a patient with SLE, the development of a new, severe headache is cause for concern, and assessment is necessary right once. For an adolescent suffering with a chronic illness, depressive affect may be a typical and acceptable response. Declining academic performance and modest issues with working memory and focus activities can be signs of cognitive impairment. More than a third of asymptomatic cSLE patients have cognitive dysfunction. More than 10% of all cSLE patients experience hallucinations, which are primarily visual but can also be

aural. Children frequently complain that the clock or light are distorted or that the text on the page are "popping out" due to visual distortions. In contrast to other NPSLE disorders, seizures are typically found in conjunction with cSLE rather than occurring as a standalone episode.

In the study on body Image, depression symptoms and Health Related Quality of Life in black women with Systemic Lupus Erythematosus, Jones et al. (2022) were trying to examine the connections between black women with Systemic Lupus Erythematosus (SLE) and their body image, depressive symptoms, and quality of life. To select the samples, the researchers recruited black women with self-reported SLE to complete a web-based survey. The majority of the female sample was non-Hispanic, married, and had a mean age of 33.5 years. 5.9 years had passed on average after the diagnosis of SLE. Oral steroid treatment was mentioned by 51% of responders as a method of illness management. Greater body image disruption and more severe depression symptoms than those reported by the general population were indicated by mean body image and depression scores. Greater depression symptoms and lower quality of life in the domain of role disruption were both strongly correlated with greater body image disturbance.

The study of Zhao et al. (2018) aimed to focus on Chinese Systemic Lupus Erythematosus body image disturbance issues to supplement existing studies. As part of the study, 118 SLE patients in all underwent standardised laboratory testing and answered several questionnaires. It was found that patients with SLE had Body Image Disturbances (BID) at a rate of 18.3%, which was noticeably greater than the control group's (0.8%). Patients with SLE are particularly worried about bodily changes brought on by the illness. Personal health insurance, a diabetes complication, the development of a new rash, depressive symptoms, anxiety, low self-esteem, and BID were all significantly correlated in SLE patients. Meanwhile, logistic regression analysis showed that BID in SLE patients was substantially linked with the development of a new rash and elevated anxiety.

The study led by Shen et al. (2013) aimed to determine the socioeconomic position, disease activity, and psychiatric problems that affect systemic lupus erythematosus (SLE) patients' health-related quality of life (HRQOL). Data were gathered from 210 healthy people and 170 SLE patients. All of the patients were diagnosed as having SLE and had their disease activity evaluated using the SLE Disease Activity Index

(SLEDAI). The levels of anxiety and depression were assessed using the self-rated anxiety and depression scales (SAS and SDS). The Short Form (SF)-36 questionnaire was used to gauge the patients' overall health. Path analysis was performed to examine the connections between the numerous predictors and the health-related quality of life (HRQoL) in order to shed more light on the factors that influence HRQOL. Psychiatric illnesses and disease activity both have an impact on HRQoL in SLE patients. While disease activity has a direct bearing on quality of life for lupus patients, socioeconomic position has no such effect. Depression and anxiety were important predictors of low HRQoL.

In the study on suicidal behaviour in patients with Systematic Lupus Erythematosus, Parperis et al. (2022) were trying to quantify the prevalence of suicidal behaviour among SLE patients and investigate risk factors for suicidal behaviour. According to earlier research, people with Systematic Lupus Erythematosus (SLE) are more likely to engage in suicidal thoughts, attempts, and final suicides. There is a lack of systematic data documenting the clinical traits of SLE patients and the risk factors for suicidal behaviour. 802 of the 27,106 SLE patients had suicidal thoughts (2.9%), and 87.9% of them were female. The most common comorbid mental diagnosis linked to suicide behaviour was major depressive disorder, which was followed by psychosis and social phobia. Suicidal behaviour has also been connected to a number of clinical symptoms, notably neuropsychiatric lupus, serositis, mucocutaneous involvement, and renal involvement. Furthermore, suicidal behaviour was linked to disease activity and damage indices with high scores.

The relationships between body image, self-image, medicine use, and medication adherence in SLE patients are still poorly understood. The study led by Hale et al. (2014) used a qualitative technique of inquiry to try and comprehend these experiences in a group of SLE patients. Semi-structured interviews were conducted with 15 SLE participants, including 1 male and 14 females. Their ages ranged from 22 to 57, and the length of the illness was 3 to 20 years. Significant unhappiness with body image was evident in the narratives. The most often expressed concerns—worries about looks and weight—were frequently connected to steroid use. More cordial interactions with doctors were wanted. Participants wanted to invest more in their internal idea of self-image overall. Following a lupus diagnosis, people frequently experience denial, bargaining, sadness, dread, guilt, and wrath. Just like lupus, emotions can ride like a

roller coaster. Emotional problems are fairly typical. According to estimates, more than half of all lupus sufferers struggle with their emotions as a result of their condition.

The book of Giffords (2003) details about the clinical depression accompanied with SLE. According to psychological and medical studies, 15% to 60% of people with chronic illnesses have clinical depression. Even though persons with chronic illnesses like lupus have a higher prevalence of clinical depression, not everyone with lupus experiences it. Moreover, depression in lupus has a variety of causes. Depression may have physical causes, which are thought to be connected in some way to the disease's impact on the brain or another organ like the heart, kidneys, or thyroid. Depression, however, can sometimes be a reaction to managing a chronic illness. The disease's treatment with steroids or another drug could potentially be to blame. These elements might be present in combination. Depression may also result from a person's appearance or feelings. As was previously discussed, drugs like steroids frequently alter how the body looks. A newfound lack of freedom or chronic discomfort that lasts for a long time may also be the cause of one's distress.

In a study, Phuti et al. (2019) were trying to explore living experiences, perceptions and unmet needs of South African patients with SLE. 25 SLE-afflicted women agreed to take part in the trial. They each completed in-depth one-on-one interviews to learn about their fertility, sexual health, emotional wellness, and medical problems. Software called NVivo was used for analysis. The majority of the participants were impoverished, with barely a quarter having gainful employment, and they were either of mixed racial or black heritage. The most frequent complaint, living with pain, had a detrimental influence on relationship, family expectations, social life, sleep, and activities of daily living (ADL). The majority of interviewees discussed their struggles with fatigue, and many said their tiredness was mistaken for being "simply lazy." This harmful fatigue has negative impacts on numerous ADLs, including taking care of dependents, maintaining a career, and sexual health. All individuals reported having low moods, which are frequently accompanied by suicidal thoughts. Many people had problems getting pregnant and having children, and these problems were frequently made worse by the pessimism of medical professionals, which led to confusion and depression. Physical deformities brought on by lupus-related baldness, rashes, and weight changes brought on by corticosteroids were of particular concern. These changes often affected self-image and libido, leading to strained personal relationships.

2.2.4 Economic challenges

In the study on disease costs of patients with Systemic Lupus Erythematosus", Zhu et al. (2009) were aiming to assess the societal expenses associated with systemic lupus erythematosus (SLE) patients who have flares vs those who do not, as well as to look at the effects of flare intensity and clinical symptoms. On 306 SLE patients, retrospective cost-of-illness research was conducted. Participants responded to questions about their sociodemographic characteristics, job situation, and out-of-pocket expenses. A chart review and a patient self-reported questionnaire were used to track the use of healthcare resources. The total number of flares and organs affected throughout the course of the previous 12 months were noted. The study used multiple linear regression to identify the cost predictors. Compared to patients without flares, people who experience flares spend more money directly and indirectly. Disease expenses for major organ flares are higher than for smaller organ flares. The substantial expenses linked to SLE flares could be decreased by treatments that successfully manage disease activity and avoid flares, particularly those that affect key organs.

In the study on academic outcomes and SLE, Zelko et al. (2012) aim to investigate the effects of systemic lupus erythematosus (cSLE) on academic performance and the effects of cSLE on disease state, neurocognitive functioning, behavioural/emotional adjustment, and demographic and socioeconomic status. Forty pairs of children diagnosed with cSLE and healthy best-friend controls were rated by parents on a standardized scale of school competence. Compared to healthy controls, school competence was rated as lower in the cSLE group, although the groups did not differ significantly on indices of cognitive, behavioural, emotional, or executive functioning. School competence ratings were correlated with measures of cSLE disease activity and treatment intensity.

The study conducted by Groot et al. (2020) aims to report the effects of cSLE on education, vocation and employment in a group of adults with SLE. To conduct the study, patients were seen, the medical records were retrieved to get more information. The education and the employment status were identified through well prepared questionnaires. Health-related quality of life was measured with SF36.The participants of the study were 106 cSLE patients, with a median disease duration of years. Almost all the participants agreed that the cSLE had affected their level of education. Half of

the patients had to adjust their vocational choice due to the disease. 44% of the patients who finished their education did not have a paid job. Out of the employed patients, 61% worked part-time. 51% patients were declared work disabled due to disease damage. Despite tailoring one's educational and career options to one's cSLE, the disease still has a significant impact on academic success and employment. To maximise participation in the community, patients need ongoing support that includes advice about prospective job changes as well as assistance in finding the right education and occupation.

The study on the impact of SLE on work life productivity conducted by Bakar et al. (2020) was undertaken to determine the level of self-reported job productivity impairment and Activities of Daily Living (ADL) impairment among Systemic Lupus Erythematosus (SLE) patients in Malaysia and to investigate the contributing factors. 167 SLE patients were enrolled in this cross-sectional study from the outpatient rheumatology and nephrology clinics. Face-to-face interviews were used to gather information about the patients' socio-demographics, including age, sex, ethnicity, marital status, and occupation, as well as the system involvement, age from onset, and organ damage associated with their SLE disease. Malays made up 59.3% of the patient population, followed by Chinese (34.7%) and Indians (3.6%). More than two thirds of the patients reported some level of ADL and job productivity impairment as a result of the illness. The absence rate over the preceding week was 10.4%, and over the previous seven days, indirect costs totalled 2,875.17 Malaysian ringgits (about $701.22 USD).

2.2.5 Social challenges and support systems

The study on the caregiver burden conducted by Uzuner et al. (2021) aims to examine the associations between caregiver burden and both the caregiver’s and child’s psychological symptoms in a cohort of children with SLE. In this study, 34 patients with childhood-onset SLE and their caregivers took part. Children and their caregivers who were in good health made up the control group. Parents, kids, and teenagers with and without SLE had their psychological well-being and the stress of caregiving assessed using questionnaires. According to the study, parental sadness and anxiety were positively connected with caregiver burden. Children's behavioural and peer issues were strongly connected with caregiver burden. Child's prosocial behaviours were adversely connected with caregiver burden.

The study led by Mazzoni et al. (2011) conducted a literature review to identify the link between social support and health in patients with SLE. These studies show that social support must be taken into account when forecasting disease activity, damage, and quality of life (physical and psychological components), even if it is still unclear exactly how social support affects health. The authors discuss the findings and make some recommendations that can help direct future study in this area. Finally, the findings' clinical and non-clinical implications are examined.

The book written by Giffords (2003) explains how the connections with others are impacted by the chronic conditions. Even while the constraints, physical changes, apprehension, and fears are all felt by the individual with the chronic illness, those who care about them are also affected. Due to physical restrictions (such as pain, exhaustion, or sensitivity to the sun), the person's social activities may be constrained. As a result, the diseased person's family, friends, and common activities may need to be modified. Others with lupus could discover that certain people in their lives don't understand their condition and feel uncomfortable being near them. In addition, because they are unsure of what to say, some friends and family members may shun the person with lupus.

The article of DeQuattro et al. (2020) relates socioeconomic status, health care and outcomes in SLE. People with poor socioeconomic position are disproportionately affected by Systemic Lupus Erythematosus (SLE). Evidence from the last two decades has made it possible to distinguish between the mechanisms of poverty that have an impact on SLE long-term effects. Poverty is linked to worsened SLE disease damage, higher mortality, and lower quality of life. It also exacerbates direct, indirect, and humanistic costs. Reducing inequities, enhancing access to care, and fostering resilience in people with SLE who live in poverty will require ongoing contributions from medicine and society.

The article of Nabors et al. (2015) outlines the importance of peer support and pain management strategies for the children with SLE. Due to their social isolation, low self-esteem, and struggles with neurocognitive and affective illnesses, children with SLE may find it difficult to form relationships with their peers. Isolation brought on by a chronic illness may result in fewer connections and less participation in peer-group activities. In some situations, this circumstance may pave the way for social problems during adolescence and maturity. Little is known about therapies to enhance peer

support for kids with SLE and about whether those who receive more peer support function better, suffer less pain, and have a greater quality of life.

Giffords (2003) in his book explains that group work services are a crucial component of service delivery because they assist people with chronic illnesses in accepting their impairment and adjusting to it. People who have functional limitations, physical stress, or stigma connected with chronic disease can communicate with their peers in groups, share common interests, and work on solving problems together. By sharing their own experiences with others who also have this disease, people with lupus who take part in support groups can gain from this significant intangible area of health treatment. Even though people with lupus may come from different backgrounds (such as different races, religions, or social classes), talking to people who have the same illness can help them comprehend their shared experiences and successful coping mechanisms.

2.2.6 Coping strategies to manage challenges

The study undertaken by Siobhan et al. (2021) investigated the difficulties that patients with systemic lupus erythematosus (SLE) and childhood-onset SLE (cSLE) confront in order to discover changeable effects and coping methods in patient experiences. Participants were recruited from two academic medical centres through a Lupus Registry of individuals. Thirteen persons, seven of whom (54%) with cSLE, took part in focus groups. The themes were divided into two categories: (1) issues with SLE diagnosis and management, and (2) patient coping techniques and changeable SLE experience characteristics. Participants reported five major challenges: the diagnosis journey, the public versus private face of SLE, SLE-related stress, medication adherence, and the transition from paediatric to adult care. Social support, frank communication about SLE, and excellent patient-provider interactions were among the coping methods and modifiable factors. Several interviewees emphasised beneficial lessons learnt from their SLE experiences, such as empathy, resilience, and self-care skills.

The study of Lance et al. (1995) looked at the links between coping, psychological adjustment, and functional status in 46 persons with systemic lupus erythematosus (SLE). The individuals filled out questionnaires that assessed their ability to cope with SLE, depression, and functional impairment. Passive coping methods (e.g., avoidance, wishful thinking, blaming self) were found to be strongly associated to lower

psychological adjustment and functional status in correlational and regression studies. Problem-focused coping was found to be strongly associated with lower levels of depression.

In a study, Haupt et al. (2005) were trying to evaluate a novel specific psychological intervention aimed at improving coping in patients with SLE. Most of the psychological measuring instruments used, such as depression, anxiety, and general mental burden, improved significantly over a six-month period in the 34 SLE patients (91% female, mean age 42 years). Conceptualised psychoeducational support may result in a considerable and consistent increase in SLE patients' coping skills, and hence in their quality of life.

The study of Alain et al. (2022) aimed to find the most frequent terms used by patients to describe their coping techniques in a large sample of SLE patients (N=3222), organise them into important themes, and investigate their likely association with certain patient characteristics in a large sample of SLE patients (N=3222). Five coping techniques were discovered, with each accounting for a significant proportion of total word occurrences: optimistic attitude (22.58%), social support (25.46%), medical treatments (10.77%), healthy behaviours (20.74%), and prevent stress (20.45%). Each method was statistically linked to certain patient variables including age and organ involvement.

2.3 Theoretical Framework

2.3.1 General systems theory

In his seminal work in 1969, von Bertalanffy (1969) described what has since become known as General Systems Theory, the concept that systems cannot be reduced to a series of parts functioning in isolation, but that, in order to understand the whole, one must understand the interrelations between these parts. Application of this theory rests on the assumption that most individuals strive to do good work, but that they are acted upon by diverse influences, and that functional and efficient systems not only account for, but also embrace, these influences.

2.3.2 Health lifestyle theory

According to the health lifestyle theory of Cockerham (2017), choosing a healthy lifestyle is not just about an individual's disconnected, arbitrary decisions; rather, it stands with a cluster of different patterns depending on class, gender, and other structural determinants. It focuses on how structural factors, including class, age, gender, race/ethnicity, social network collectivities, and living conditions, provide the social context for people's socialisation and social development, and that their experiences ultimately determine their lifestyle preferences and practises.

2.4 Research Gap Analysis

The review of literature points out that number of studies have already explored into the SLE, its challenges and correlation with multiple factors such as age, gender, colour, race, socio economic status (SES) etc. Although most of the studies reviewed have their roots in the western countries, it delineates the physical, psychological, economic and social challenges of SLE. From the review, it becomes clear that SLE is a disease with thousand faces, affecting the body’s healthy tissues and organs. The failure for an early diagnosis brings with it further complications. All the studies unanimously state that the disease condition has an adverse effect on the health-related quality of life. Most of the studies throw light on the fact that childhood onset SLE has adverse effects on the all the dimensions of the patients. The literatures outline the various symptoms that might accompany SLE. It can include extreme tiredness (fatigue), discomfort or illness, fever, loss of appetite, weight loss, joint pain, muscle pain, weakness. Skin problems pose threat to individuals with SLE etc. Among these, the fatigue and the joint pain have a heavy toll on the physical and functional abilities and emotional health of the individuals. The fatigue makes one less interested in pursuing one’s dearest hobbies. The association of fatigue with the workplace disability is emphasized by few studies. The complications of the drugs and medication is clearly pointed out by few literature studies. Abundant studies identify the psychological effects of SLE, which consists of depression, mood disorders, suicidal ideations, lack of self-esteem.

There are also many literatures that throws light into the treatment costs, both direct and intangible. Undoubtedly, the childhood onset SLE affects the school attendance, workplace quality of the caregivers, increases the caregiver burden etc. The studies

prove that the social support and peer group relationship will have a positive effect on the overall health of the individuals with SLE.

While analysing the literatures available on the area of the topic, the researcher could identify certain gaps, which would be filled with the present study. The studies undertaken are mostly from the Western backgrounds. Though the prevelance and incidence of SLE is increasing in India, studies that are based in Indian context are hardly few. Also, the majority of the studies were done using the quantitative research design. Only a few have attempted to bring to light the lived experiences of people living with SLE. As the review of the literature points out, studies that detail the features of childhood onset SLE are scarce. Moreover, the nature of SLE, challenges and coping strategies in Kerala has not been studied yet.

CHAPTER THREE: METHODOLOGY

Chapter Three: Methodology

3.1 Overview of the Chapter

This chapter deals with the methodology adopted for this study. An attempt is made to narrate the methods and techniques used to identify cases with Systemic Lupus Erythematosus (SLE), the physical, psychological and social challenges faced by the children and their coping strategies. This chapter will delineate the adopted research design, pilot study, the setting for the study, population, sample, tools, and method of data collection and how the data will be analysed and interpreted in order to arrive at certain findings, suggestions and conclusions based on the study.

3.2 Title

Challenges and Coping Strategies of Children with Systemic Lupus Erythematosus (SLE).

3.3 Conceptualization

The various concepts used in the study have been evolved from the detailed literature review on the topic.

3.4 Definition of Concepts

3.4.1 Challenges

Theoretical Definition

Challenge refers to a situation or task that demands effort, skill, or determination to overcome obstacles or achieve a particular goal. It often involves difficulties, risks, or complexities that require individuals or organizations to push their limits, develop new strategies, and exhibit resilience (Daft, 1983)

Operational Definition

In this study, ‘challenge’ refers to external/physical changes in the body to the onset of SLE. This may include disease symptoms (presenting and recurrent), complications associated with the diagnosis and medication, fatigue, change in body shape, impact on

the Activities of Daily Living (ADL), physical health of the children affected with Systemic Lupus Erythematosus (SLE).

In this study, ‘challenges’ also refers to the emotional and mental risks of children with SLE. This may include anxiety, depression, stress, low self-esteem, identity issues caused by altered body images, due to the impact of the disease on their lives, treatment regimens, and potential limitations they may face.

In this study, ‘challenges’ refers also to problems that children with SLE may experience in their interactions with peers, family members, and society at large. These difficulties may include a sense of loneliness, a lack of social interaction, difficulties in disclosing their disease status and potential stigma associated with their sickness.

In this study, ‘challenges’ also refer to the economic impacts of SLE on the children and the family. This may include medical expenses, treatment costs (direct and indirect), healthcare access, educational impact, parental employment etc.

3.4.2 Support system

Theoretical Definition

"Support system refers to a network of individuals, resources, and structures that provide assistance, encouragement, and aid to individuals or groups in need. It encompasses both formal and informal sources of support, such as family, friends, communities, organizations, and professional services, that contribute to the well-being and functioning of individuals or groups in various domains of life." (Berger, 2014)

Operational Definition

In this study, the support systems refer to the available resources and services for the benefit and care of children diagnosed with SLE. This can include the support provided by parents, family, health caregivers, different institutions like religion and political.

3.4.3 Coping strategies

Theoretical Definition

A standard definition for coping strategies refers to the conscious efforts and behaviors individuals employ to manage, adapt to, or deal with stressful or challenging situations. Coping strategies can include a range of approaches, such as problem-solving, seeking social support, emotional regulation, positive reframing, or engaging in relaxation techniques, with the aim of reducing distress and enhancing overall well-being (Lazarus & Folkman, 2013).

Operational Definition

The operational definition of coping strategies could involve the specific techniques reported by children with SLE and their families to manage the physical, psychological, social, and economic challenges associated with the condition.

3.4.4 Body image

Theoretical Definition

Body image refers to a person's subjective perception, thoughts, feelings, and attitudes about their own body, including its appearance, size, shape, and functionality. It encompasses both how individuals perceive their own bodies and the emotional and cognitive evaluations they attach to their body image (Cash & Smolak, 2011).

Operational Definition

In this study, 'body image' refers to the perception of the children with SLE about the changes in their bodily stature due to medications and disease activities and satisfaction about the body appearance.

3.4.5 Direct costs

Theoretical Definition

The theoretical definition of direct costs refers to the expenses that can be specifically attributed to a particular activity, project, or product (Kapla, 1998).

Operational Definition

In this study, 'direct costs' refers to the specific expenses directly associated with the diagnosis, treatment, and management of SLE. These costs could include medical

consultations, laboratory tests, medications, hospitalizations, surgeries, rehabilitation services, and any other healthcare-related expenses specifically attributable to SLE.

3.4.6 Indirect costs

Theoretical Definition

The theoretical definition of indirect costs refers to the expenses or costs that are not directly attributed to a specific activity, project, or product but are still incurred as a result of the overall operations or existence of an organization or activity. These costs are not easily traceable to a specific output but are necessary for the functioning and support of the organization as a whole (Horngren, 1972).

Operational Definition

It refers to the costs that are not directly attributable to the diagnosis, treatment, or management of SLE but still arise as a result of the condition. These costs could include factors such as productivity losses due to absenteeism or reduced work capacity, informal caregiving costs, transportation expenses, and other non-medical costs associated with the impact of SLE on daily life and functioning.

3.5 Research Questions

1. What are the challenges- physical, psychological, social and economic- faced by the children with SLE?
2. What are the coping strategies used by the children with SLE to manage the challenges?

3.6 Research Approach

Qualitative approach is adopted for the study and multiple case study design was used to collect data for the purpose of the study. Qualitative research refers to a research approach that focuses on exploring, understanding, and interpreting phenomena through non-numerical data. It involves collecting and analysing rich, descriptive data such as interviews, observations, documents, and artifacts, to gain in-depth insights into the underlying meanings, perspectives, and experiences of participants (Merriam, 2009).

3.7 Research Design

A research design refers to the overall plan or structure that guides the collection and analysis of data to address a specific research question or objective. A research design provides a roadmap for conducting the study and ensures that the research is systematic, rigorous, and capable of generating meaningful and trustworthy findings.

The research design adopted in this study is multiple case study research design. The case study research design is an in-depth study of a particular situation rather than a sweeping statistical survey. Case study research is an in-depth and comprehensive investigation of a particular individual, group, event, or phenomenon within its real-life context. It involves a detailed examination of a specific case to gain a deep understanding of its unique characteristics, dynamics, and complexities (Męcfal, 2012).

3.8 Pilot Study

The researcher conducted the pilot study on two children diagnosed with Systemic Lupus Erythematosus, hailing from the districts of Idukki and Pathanamthitta. From this the researcher understood the feasibility of the study. Appropriate modifications were made to enhance the instrumentality of data collection tools.

3.9 Research Site

The study was carried out at the houses of the children diagnosed with SLE. The researcher conducted home visits to gather information from the children and the caregivers about the various physical, psychological and social challenges faced by them during their life journey with SLE.

3.10 Sampling

A non-probability, purposive sampling method was used to select the sample for the study. The participants have been chosen to participate in individual face-to-face semi structured interviews. Participants for the study have been selected according to a set of specific criteria.

3.11 Inclusion Criteria

Adolescent children with SLE belonging to the age group of 10-19.

Children with SLE and the families that have consented to give the interview.

Children with SLE living in Kerala.

3.12 Exclusion Criteria

Children with SLE falling outside the age group of 10-19.

Children with SLE and the families that have not expressed their content for the interview.

Children with SLE living outside Kerala.

3.13 Sample Size

For the present study, a total sample of 5 adolescent children diagnosed with SLE who were satisfying the exclusion and inclusion criteria were selected.

3.14 Sources of Data

Primary Data

Primary data were collected directly from the children diagnosed with SLE and their families.

Secondary Data

Secondary data comprises of information from literature pertaining to Systemic Lupus Erythematosus, its physical, psychological and social challenges, telephonic conversations with specialists in rheumatology, short interviews with doctors and television programs of doctors specialised in the treatment of Lupus.

3.15 Tools for Data Collection

The interview schedule was prepared to find out the socio-demographic profile of the children with SLE. This schedule consists of closed questions, dealing with the socio-demographic profile like “age, educational status, geographical location of the house, name and occupation of parents, siblings, hospital where treatment is done, age at the diagnosis” of the children.

A semi structured interview guide including more than 60 questions was prepared based on the research questions. Certain modifications were made to the questions following the pilot study. In depth interviews and discussions were conducted as the techniques of data collection to draw information from the respondents.

Non-participatory observation was used by the researcher to observe the financial status and quality of caregiving of the family. This has contributed in making the study rich.

3.16 Data Collection

The researcher collected the data from five adolescent children diagnosed with SLE and their family. the researcher visited each family of the children and personally interviewed the children and the caregivers. Each interview lasted for one to two hours. The researcher had collected the details of the children from three hospitals in different districts. The researcher had collected the secondary data from the telephonic conversations and interviews with doctors specialised in rheumatology. The interview guide was originally made in English and was translated into Malayalam for the purpose of the interview.

3.17 Data Analysis

The data gathered through in-depth interviews is submitted to thematic analysis with the main goal of understanding the study problems from the viewpoint of the experience of the individuals. Data analysis was done based on the following research questions:

- **What are the challenges-physical, psychological, social and economic-faced by children with SLE?**
- **What are the coping strategies of the children with SLE?**

3.18 Ethical Consideration

Permission was obtained from the Principal of Loyola College of Social Sciences and the Head of the Department of the Social Work to approach the different hospitals to seek permission for the data collection. Verbal consent was taken from all the respondents before conducting the interview after communicating with them the purpose of the study and affirming that full confidentiality would be maintained and the data collected would not be used for any other purpose other than this study.

3.19 Assumptions, Limitations and Scope

Assumptions

The researcher assumes that the experiences, including the challenges and the coping strategies of the participants can be applied to the other populations also.

Limitations of the Study

- The samples selected for the study were different in terms of the type of SLE and the degree of the severity of the disease condition.
- The samples selected followed different streams of medicine. Thus, there was difficulty in observing the commonalities in the medication and its side effects.
- Since the disease is a rare one, the researcher faced difficulties in identifying the cases. The samples selected were from different districts. Thus, the researcher had to travel a lot to reach the samples.
- The few samples identified were often unwilling to provide consent.
- The researcher was not well versed in the medical explanations of the disease and the medical terminologies.
- All the samples selected were from the rural areas.

Scope of the Study

The study will help the healthcare professionals to evaluate themselves and to develop understanding about the diverse needs of the children with SLE. It also will enable the policy makers to take notice of the manifold challenges affecting the children with SLE. Along with contributing to the existing body of knowledge on SLE, the study also puts forward some useful recommendations.

3.20 Summary of the Chapter

Methodology plays a significant role in the research process. It paves the way and provides guidelines for the researcher to conduct the study, analyse the data and draw conclusions using scientific tools and approach. Having a methodology in fact make the research journey smooth. The above chapter provides a vivid picture of how the study is going to be carried out. It lays down the objectives for the study, definition of the concepts involved, research approach, design, source of data, tools for data

collection etc. Finally, the chapter also includes a portrayal of the exclusion and inclusion criteria and the limitations of the study.

CHAPTER FOUR: CASE DESCRIPTIONS

Chapter Four: Case Description

4.1 Overview of the Chapter

The chapter presents the experiences of five participants diagnosed with Systemic Lupus Erythematosus (SLE). For confidentiality reasons, the participants are marked by the letters, **A,B,C,D** and **E**. The experience of the participants is reported both in verbatim and narrative. The case descriptions contain details such as the demographic profile, physical, psychological, social and economic challenges faced by the participants. Upon a careful reading, one will know that the chapter flows logically and thematically.

4.2 Case 'A'

The first participant, case 'A' is a seventeen-year-old Christian belonging to an upper middle class family. Her family consists of her father, mother and two siblings. She has completed her high school studies and at present is doing her plus two studies in a school which is 22 kms away from her house. Her father (52), after completing his high school studies, got engaged in wood business. His business grew gradually and the family is financially stable now. Her mother (50) is a housewife, caretaking 'A'. The elder sister of 'A' is pursuing her degree in nursing from a college in Bangalore. The younger brother is at the tenth grade in a nearby school. The family resides in the rural part of the district of Kottayam, Kerala. Geographically, the land is a plain one with no extreme weather conditions. The interested hobbies of 'A' are reading and writing.

'A' was diagnosed with Systemic Lupus Erythematosus (SLE) while she was sixteen years old. In the initial stages of the disease (six months before the onset of the disease), as per the narratives of the parents, there were few symptoms like fever, head ache, red rashes on the skin, acute pain on legs and hair loss. 'A' said: "*I saw some rashes on my skin before I was diagnosed with SLE. After two or three days, the red rashes turn into black colour, later the rashes disappear. After that, there was severe hair loss.*" At this stage, parents did not consider this much serious. During the visit of a family friend who is settled in United Kingdom (UK), she took notice of the changes observed in 'A' and the frequent fever and advised the parents to take her to a hospital. Actually, she said this out of her experience. Thus, the parents took 'A' to a neighbouring clinic.

Following the guidance of the doctor, 'A' was taken to a government hospital. Since the treatment was not satisfactory, the parents took her to different private hospitals. At a private hospital in Ernakulam, following a series of tests, the doctors reached the conclusion that 'A' is diagnosed with mild Systemic Lupus Erythematosus (SLE). The treatment in this hospital lasted around two months. Since the treatment was costlier and the hospital was far away from home, the parents decided to seek treatment from a popular hospital which is not that far from the house. The family and the healthcare professional at hospital were quite happy since SLE could be diagnosed at its onset and without any delay.

The treatment in the hospital is quite satisfactory. In the beginning, they visited the hospital every month. Later, as per the instructions of the doctors, 'A' visit the hospital once in two months. During every visit, the blood and urine tests are customary. To manage the symptoms of the disease, the doctors prescribe steroids. While narrating the side effects of the medications, 'A' was seen talkative. She started explaining things one by one and in detail. She explained that although the medications were successful to manage the symptoms, she had to go through severe hardships. She said that she lost herself in the process of treatment. She has put on wight as a result of taking steroids. She was 33kg before the onset of the disease. Within a year, she gained 57 kg. 'A' said: "*Yes, the medicines have reduced my pain to a great extent. But in the process, I have lost myself. My weight increased rapidly because of the medicines from 33 kg to 57 kg".* She further narrated that the medications have resulted in loss of appetite, mood swings and sleep disturbances. From the descriptions, it was clear that 'A' is not happy with the kind of medications and treatment that she receives. She shared that she would not put on height due to the medications. She was of the opinion that the healthcare professionals should share with the patients the details of the disease. Many times, she felt that the doctors disclose the details to the parents and not to her. 'A' has various doubts regarding the disease and her health.

The symptoms like fever, red rashes on hands and legs and hair loss have now subsided due to the treatment and medications. The physical challenges associated with SLE do not affect 'A' now much. At the time of the diagnosis, the patient found it extremely difficult to engage in physical activities due to the acute pain. As per the narratives of 'A', she faced troubles in walking, running, participating in sports activity or exercise, lifting heavy things, doing the chores around the house etc. But she could manage to do

her personal tasks by herself. She did not need any external support to take a bath or shower. Until then, she used to assist her mother in keeping the house and the courtyard clean. In the evening, following the tuition classes, ‘A’ used to play badminton games along with the family members. Sometimes, she had the habit of riding bicycle and reading fictions in her free times. From the narratives of the parents, it was clear that ‘A’ was always cheerful and happy girl. ‘A’ finds it difficult to cope with the fatigue associated with SLE. She finds no interest in doing things. The previously interested hobbies like cycling, badminton and reading no longer help her. Earlier, she used to dance and sing in her free times especially before the parents. She had spent time in mobile phone as a time pass. She was active in Instagram and WhatsApp. What troubles her most is the frequent head aches and low level of energy. She feels tired soon and wants to go to bed always. Also, she had missed a lot of school working days as a result of the disease.

The significant impact of SLE on the health of ‘A’ was in the form of fatigue and loss of energy. She explained that she experiences fatigue in its intensity. She finds it really difficult to engage herself in any physical activities. Her interested hobbies like reading, singing and dancing are no more favourable for her. She is unable to engage in sports activities like cycling, playing badminton etc which she was earlier fond of. Though she is interested to do yoga and go to gym, the fatigue does not allow her to do these. She used to go with her father for the morning walk some days in the past. But now, she struggles to engage in activities of this sort. Her father has brought home a device to help her put on more height. But the energy level is so less that she feels unable to engage in such activities. The doctors had advised her to occupy herself with any activities to manage fatigue. She tried various alternatives and found nothing useful. She tried solving the fatigue by using phone, chatting with friends and family members etc, but none of them worked. Finally, she turned to sleeping as a remedy. ‘A’ admitted that even sleeping is affected because of the medications.

While explaining the details concerning the pain, ‘A’ shared that she has frequent acute pains in the neck. Thus, she finds it extremely difficult to carry school bags. Since she needs to walk a short distance every day to reach school, she faces struggles. She finds it hard to manage the pain on legs. During such times, she finds relief in her mother who used to massage the legs. The toilet and latrines at the school are not favourable

for her. Her condition makes it difficult for her to attend the school with proper concentration. Due to these difficulties, she scored less for the exams at plus one level.

Another area where 'A' struggles most with the SLE is the psychological. The patient goes through many negative feelings as 'A' terms it. She shared that she goes through the feelings of isolation. She feels that no one loves her and cares for her. She is less hopeful about the future as she thinks that she would not be successful in the future due to her disease conditions. Her dream before the onset of the disease was to become a chartered accountant. But now, she plans to do her degree studies in nursing as her elder sister since she believes that she would get job for sure. She experiences herself as weak. Earlier, she used to be bold and determined. She could take decisions for herself and make strenuous efforts to realize the decisions. But, now a days, she feels powerless to control her own mind. She feels deeply hurt by the comments of the people. She finds it hard to accept her disease condition and her body image. She feels that people around her are staring at her without empathizing with her. What she finds most difficult is to tolerate the comments of body shaming. The parents expressed that 'A' has developed strange habits like crying always and anger issues. In the initial stages of the disease and the medication, she had hallucinations. She had frequent doubts that people are planning plots against her. At the onset of the disease, 'A' had suicidal ideations. *One evening, I made everyone shocked by a strange behaviour. I was mentally down throughout the day. I had experienced severe mood swings and was crying many times. On the evening, I ran out of the house with a knife crying aloud and went to the house of my grandmother. People in the neighbourhood saw me crying and running with knife. The father followed me in a rush and prevented me from the suicidal attempt. There was a similar instance at a later time. I climbed on the top of the house with the intention to hurting myself by jumping down"*. Since the parents were observing every movement of 'A' closely, they could save her life. The only sources of support at the moments of emotional breakdowns are the parents.

Another area where 'A' struggles most is lack of self-esteem. The issue of obesity resulting from the medications has caused insecurities for the patient. She is unable to accept her bodily features. The fact that she would not put on more height makes her upset. She feels that everyone around her makes shame of her for her obesity. Even the passing comments from the part of the cousins or close friends about her body makes her angry. She feels that her elder sister too makes fun of her. The reason why she stands

aloof is her fear of body shaming. Though she has an urge to do exercise or go to gym, she has not yet experimented it because of fatigue. She worries that she has lost her beauty and assumes that she is no more presentable before others. The inability to accept herself has made her less confident. 'A' accepts the fact that there are a lot of behavioral changes in her with the onset of the disease. She is not satisfied with herself.

The social life of 'A' had significant setbacks due to SLE. In her old school, she had a good number of friends. She used to call them every day. But in the new school, the situation is bit different. Her friends have moved to other colleges. Moreover, she feels that her classmates are not that bothered about her. Since she does not expect any sort of sympathy from others, she has not yet disclosed her disease conditions to her new friends or teachers. She feels that they cannot understand her better. She is less interested in attending the social functions. Earlier, she used to go to theatres with the family, go for school picnics, attend Sunday services in the church etc. With the disease, she finds it difficult to stand in public. Her views about the society is pessimistic. She feels that the society around her finds fault with her always. Her parents are also not comfortable with the society. They feel shy because of the events on that evening when she attempted suicide before others.

Since the family was economically above average, they managed to meet the treatment expenses. Before the diagnosis, the father had accidentally purchased the insurance policy of STAR HEALTH. This helped him manage the economic costs of SLE. The father admitted that they would find it hard to meet the direct costs of SLE if there was no insurance. Moreover, the doctor had helped him to buy medicines from the company directly.

'A' is happy to speak about her previous school, teachers and friends. Both her parents and herself spoke a lot about the mathematics teacher who devoted her time for the development of 'A'. She was ready to explain every problem related to the subject always. Likewise, the support extended by the friends were praiseworthy. The comforting presence of the priest of her church was a source of support. At the same time, she is dissatisfied with the kind of services she received form the health workers. She feels that the doctors in few hospitals have not communicated to her the details of the ailment. This has forced her to turn to alternate sources of knowledge. Though she is dissatisfied with herself, she is regular in prayers and has a deep faith in God. The

support of the parents was a real source of relief for ‘A’. Whereas, the indifferent behaviour of her siblings and friends makes her sad.

4.3 Case B

Case ‘B’ is 18 years old adolescent girl doing first year degree studies in economics from a popular college in the district of Kottayam. She belongs to a Hindu family. Along with the formal studies, she also undergoes training as part of preparation for civil service examinations. The family consists of three, ‘B’, her mother, sister and grandmother. The mother of ‘B’ is employed as an attendant in a govt hospital and is 55 years old. The grandmother aged 88 years old is suffering from age related ailments. Her younger sister does her plus one studies from a nearby school. ‘B’ lost her father eight years back due to a heart failure in 2015. He was working as a AC mechanic in Dubai. The death occurred while he was on his vacation. The house is located in a rural area, the geographical nature of which is plain and with no extreme weather conditions. The interested hobbies of ‘B’ are story writing, playing violine etc. Due to severe pain, she stopped learning violin.

While describing the experiences and story of the journey with SLE, she seemed to be quite calm, relaxed and of sound health. She showed no signs of obesity, hair loss, skin rashes etc. She seemed to be normal like any other individual. Her journey as an SLE patient started five years back in 2018. Turning back the pages of her life, she started explaining the details of her disease and those painful memories. It all starts with black rashes on right leg. She did not consider it serious. Later she began to experience acute and intolerable pain on her legs. The pain began to spread to other leg and hands. Since the pain was unbearable, she was taken to a nearby popular private hospital in kottayam. She was given pain killer tablets and not more than that. She feels that she was not well treated there. In the opinion of ‘B’, the doctors failed to take the case history and identify the root causes. After few days of admission, when the pain turned to be more intense, the doctors advised amputation of the right leg as a solution. The family was shocked and they decided to take a second opinion. This time, they sought the treatment from the Ayurveda stream of medicine. ‘B’ was given certain medicines and the pain was not subsided. Her cousin who is a doctor heard of the condition of ‘B’ and took her to a famous hospital in Madurai for better treatment. After detailed examinations, the doctors diagnosed her with Systemic Lupus Erythematosus (SLE). Though the doctors

advised the family to continue the treatment there, they shifted to a well known private hospital in Ernakulam, Kerala for convenience. She was given proper medication and treatment in the hospital. With the medicines, the pain got subsided and she began to regain the quality of life. ‘B’ was discharged from the hospital with the advice that she shall not fail to take the prescribed drugs. For three years, everything was fine for her. But, at a certain point of time, she stopped taking drugs for no reasons. She assumed that there would be no problems even if she stops to take drugs.

In 2022, ‘B’ had severe bleeding associated with the menstruation. The bleeding continued for three months. During that time, she used to take tuition classes for the children from the neighbourhood. The bleeding was so frequent that she could not travel outside. She stopped attending classes. The flow of urine was also not normal. Since she had no idea about what was going on in her body, she was guided to a gynecologist. The amount of hemoglobin went below the required and thus she was guided to the hospital in Ernakulam. She needed blood transfusion and the doctors advised the family to do the process in neighbouring hospital. Thus, ‘B’ moved to a hospital for blood transfusion. The condition got aggravated in the hospital. She was admitted in the hospital for six continuous days. The pain turned to be severe and unbearable. She began showing strange behaviour. There was huge swelling on both legs. Her body weighed 70 kg at this point of time. The pain killers could not decrease the pain either. On the sixth day of the admission, she began to lose the eyesight of her right eye. Since the eyesight was completely lost, the doctors advised the family to go to the hospital in Ernakulam for the further treatment. By the time she reached the hospital in Ernakulam, the SLE had affected various organs of the body. She almost lost her memory due to severe pain. Later she had episodes of seizure. Within a week, she regained her health and the pain got subsided. Gradually, she began to lose weight and it has reached 50 now. She was given two injections of Rs 32000 each to reduce the swelling. Now she goes hospital once in two months. During every visit, the blood and urine tests are done and the medicines for the months are provided. At a point of time, she had to take 13 drugs after the breakfast every day. As the disease turned to be mild, there was a reduction in the number and dosage of drugs and the frequency of hospital visits. To avoid the obesity issues due to medications, ‘B’ started diet. She avoided sugar, bakery products, reduced rice etc.

In 2018, when the pain on legs got intense, she missed many school days. She found it difficult to do the physical activities like walking, running, participate in sports activity or exercise, lift heavy things, take bath by herself etc. She could not dress up herself in those days. While admitted in the hospital and when the pain got intense, she used to cry aloud, undress herself and try to get out of the bed. There were changes in the colour of the skin. Apart from the pain on legs, she had back aches and head ache. What troubles 'B' most is that there is no menstruation now for the last six months. While the disease was active, 'B' experienced fatigue in its intensity. She always felt to sleep. If she fell to sleep, it would be deep sleep. The laziness due to fatigue did not allow her to engage in any of the household chores. 'B' reported that she had determination even while she experienced fatigue. She could force herself to assist mother in few activities.

Few hospitals provided information of the disease and provided her emotional support while few others had no idea of what she was going through. She sometimes searched the details of the disease in google. 'B' feels that certain doctors were quire insensitive to the symptoms of the patient. The mother reported that the doctors were comforting her and offering her support.

While speaking about the psychological challenges of the disease, she said that she never experienced tensions, suicidal ideations or isolation. She developed uncontrollable anger in association with the disease. Even in the midst of all her sufferings, she stood courageous. When the disease was active, it was difficult for her to accept the disease condition and feared that she would die earlier. 'B' also had difficulties in accepting her skin conditions. She felt shyness because of her skin issues and did not want to appear before the public. She remained in the house nearly one year without talking to anyone.

After the onset of the disease, 'B' experienced difficulties to engage in social activities. Prior to the disease, she used to interact with her friends freely and was active in the social media chatting with the friends. But the disease has made drastic changes in all these habits. Before the onset of the disease, 'B' was interested in sports, especially, athletics and moreover she was an active blood donor.

The family has not disclosed the details of the disease to the public and even to the health department. Though the neighbours have certain doubts, they are not clear. Mother hesitates to disclose as she feels that the public is not aware of the disease and

may develop their own assumptions. The ‘B’ feels no issues in disclosing the details. Most of her cousins already know it. She had missed many of her college days due to pain and hospitalization. Thus, it had affected her scores. She had to stop the civil service training in between when the pain was acute. Likewise, she was forced to stop her computer training classes because of the disease.

The sources of support during the disease were family, cousins, doctors, few relatives and teachers. At the same time, ‘B’ felt that she would have been much better if the healthcare professionals in the hospital in Kottayam supported her better.

Mother shared that the economic costs of the treatments were quite expensive. Since she was the only breadwinner, she had to go through a major crisis. She was forced to sell all the gold and a portion of land for the purpose of treatment. A lot of people pitched in to help the family in the treatment. The total expenses incurred for treatment would amount up to 8 lakhs. Now, every month, the family spends Rs 12000 every month on treatment. The only source of the livelihood is the income from the tiny grocery shop and monthly salary of the mother which is only Rs 10000 now. The family has not bought any insurances so far.

The future aspiration of ‘B’ is to win for the civil service examinations and contribute for the general public.

4.4 Case ‘C’

Case ‘C’ is a nineteen-year-old young girl hailing from a mountainous region of Kerala. She does her B.Com studies from a private college in Kerala. The family is financially backward and struggling to meet the both ends. Her father was working as a supervisor in an estate but now jobless due to seasonal changes. At present, he is working for daily wages. He cannot to go for job to far places since his presence is needed in the house considering the disease condition of ‘C’. When there is unbearable pain, ‘C’ needs hospitalization in the nearby cooperative hospital. Usually, the pain gets aggravated in the late nights. Therefore, the presence of father is a must. Her mother is engaged in the household chores and caregiving role. Earlier, she used to work as a daily wage labourer in a nearby estate. But now, she is unable to go for work since ‘C’ needs a caretaker always at home. Her younger sister is doing the plus one studies from a govt school in the locality. She was diagnosed with SLE at the age of 17. But the symptoms had started

appearing when she was 13 years old. At present, she is undergoing treatment from a private hospital in Kerala. The interested hobbies of 'C' are hearing songs, reading and writing. She is also interested in playing badminton, carroms, walking, cycling etc. Though she gives a try, she feels it difficult to carry on since the pain becomes acute on the joints.

At the beginning of the interview, 'C' was seen quite sad. When asked, she said that she is having severe headache. The father of 'C' shared that she has developed swelling on face very recently. Father doubts whether it would turn into a severe pain and hospitalization for which the family is less prepared considering the financial conditions. The symptoms of SLE started with the hair loss. At this time, she was at the eighth standard in the school. Later on, she began to experience headache, vomiting, eye pain, dizziness. The parents got frequent phone calls from the school saying that 'C' has fainted. "*I used to faint in the class many times. Those times, my parents used to get frequent phone calls from the school that I have fainted down. The teachers wanted me to consult a doctor soon".* Thus, she was taken to a hospital nearby for medications. Though she was given medicines, the situation was not under control. Moreover, it was very much difficult for her to walk to the school with the bag. Rashes began to be seen on the face. There were black rashes on many parts of the body. Thus, she was taken to a new hospital. The blood tests proved that the amount of HB and platelets are very low. The doctors referred her to govt medical college. After a series of medical examinations and tests in the medical college, 'C' was diagnosed with SLE. Since there was no treatment available for SLE in the medical college, the doctors shared the details of the hospitals which provide standard care for people with SLE. The parents finally selected a well known hospital for treatment. Up until now, 'C' had admissions in the hospital several times. Based on a number of tests, the hospital has come to a conclusion that 'C' has developed MCTD (Mixed Connective Tissue Disease), which is an extreme condition of SLE. The doctors in the hospital corrected the assumption of the family that 'C' has SLE. 'C' had participated in a TV program called '*udan panam*' to raise funds for treatment and describe about the severity of the illness to the public. During the program, she stated that she was having SLE. The doctors had watched the program and corrected the misconceptions of 'C'. She goes to the hospital every month now. Medicines for every month are prescribed after detailed check ups. The symptoms that 'C' experience now are joint pain, swelling on face,

headache etc. When the climate gets cold, the joint pain gets aggravated. Getting exposed to sunlight makes her easily tired and creates butterfly rashes. When there is pain, she finds it difficult to walk, even if it is a short distance. Sometimes, her mother used to massage over the body when faced with extreme pain. But this often aggravates her pain. Sleeping also does not work for her when the pain is intense.

When there is pain, 'C' is unable to any activities of the daily life. she cannot even walk or lift her legs to climb the stairs. The available option when faced with severe pain is to get admitted to the nearby cooperative hospital where she would be supplied with 3 large bottles of drip. It will take minimum six hours to complete the process. Finding the proper vein for injection is a matter of difficulty since there is swelling. Travelling all the way to the hospital in the late night has become a difficult thing now. The rickshaw drivers are hesitant to pick their phone calls in the late night. Since they have only a scooter, they have no other way than to depend on the benevolence of the drivers. Mother shared her experiences of sleepless nights in the hospital. The family is afraid of the rainy seasons as the climate would trigger pain and the disease symptoms. When there is pain, she cannot attend the school or college and thus she had missed many working days in school and college. The pain had impacted the exam scores. She finds it impossible to bath by herself or wash her clothes. She is able to lift anything when there is pain. She cannot even drink a glass of water by herself. Even fingers start swelling. She can't feed herself or fold the hands and legs. 'C' said: "*One day, I was admitted in the hospital. On a night, I got severe pain and started swelling all over the body. Suddenly, I could feel that my dress began to tear".* Since the family has not got well, they buy water every month. Since there are no pipes inside the house, the younger sister helps in fetching water and drawing it near to 'C'. The pain she usually experiences include joint pain, leg pain, headache, eye pain etc. When there is pain, she either cries aloud or gets angry. At present, she takes five tablets every day. Comparing to the previous situation, 'C' is progressing due to the medicines. Since few tablets are steroids, they have side effects like swelling. If she misses medicine, she develops severe pain and the treatment gets complicated. Doctors are working on to get the doses decreased. Another triggering factor for pain is tension. 'C' has increased pain when tensed. Apart from the treatment, the healthcare professionals had offered counselling and health education. 'C' feels that the doctors have not disclosed all matters to her. Sometimes, doctors disclose the seriousness of the disease to the mother only. When

the mother becomes sad and are in tears, doctors used to comfort mother and tell that she shall not cry in front of 'C'.

The family now aspires to move to a hospital in Puducherry for a better treatment. They have heard of the hospital from a person unknown to them. Once they received a call from on old man living in Kochi, Kerala. Understanding the disease condition of 'C' from a television program called '*udan panam*', the man called and shared his experience with Lupus. He shared that he lost the life of his grandchild due to SLE. The treatment that he received from a hospital, according to him, was not proper. He heard of the hospital in Puducherry from his friend who had experienced recovery from SLE in the hospital in Puducherry. The financial issues are also a factor that motivate the family to think of another hospital.

While describing the fatigue associated with the disease condition, she described that it is a terrible experience. When 'C' feels fatigue, she tries to elude it by sleeping for long ours. But, when fatigue is associated with pain, this strategy does no work well. At these moments, she does not feel to take food. If at all she takes food, she starts vomiting. Spending time in mobile phone is also a strategy. But when the fatigue extends for a long time, even phone becomes boring experience. Since she knows the disease for long, she is able to accept the disease and its consequences. She has prepared her mind to face the struggles of the disease.

The sickness has by now affected her psychic wellbeing. Sometimes, she feels it better to die soon. She has continuous mood swings. At certain moments, she thinks that the disease conditions will change and she would be back to the normal health. When the pain is moderate, she maintains an optimistic mindset towards the disease. She admits that she was able to accept the disease. At certain times, she questions why she alone has to go through this pain while children of her age enjoy their life. 'C' has developed anger with the onset of the disease. She always maintained a calm personality but the pain makes her sensitive to everything surrounding her. She is easily irritated and turns angry at everyone and everything. She feels that the attitude and the approach of the doctors, friends and teachers give her comfort and encouragement when she is emotionally upset. She feels sad also because of the body image. Before the diagnosis, she weighed only 40 kg. Later, she increased weight and reached 110 kg. Now, she is of 66 kg. Though uncomfortable, she has no issues in interacting with others because

of her body image. Because of the very nature of the disease, she is restricted from attending social functions because of the probability of getting infections.

She is happy to think of her friends. She has understood the value of friendship since her friends always supported her in times of pain. They call her frequently or message to make sure that she is fine. Even the teachers call her frequently. They consider her as one among them. They do not treat her as a patient. The friends used to send her voice notes and share the learning materials through phone. The attitude of the society towards her is disgusting. Some people think that 'C' is taking rest out of her laziness or acting as a patient. While they see 'C' travelling with her father in the scooter, people make comments that the parents are spoiling her without making her walk or work. 'C' feels sad at these comments since her parents and family are affected because of her sickness. The mother of 'C' is a member in the kudumbasree and while attending the meetings, other members make negative comments about 'C' without properly understanding her conditions. 'C' feels no issues in disclosing the disease conditions to anyone but is not interested in getting the sympathy of the others. She had find faults with her mother sometimes when she narrates all the story to the strangers or the rickshaw drivers. 'C' said that she has missed lots of school and college days due to the disease. She feels that she has not enjoyed the beauty of the college life and she has no cherished memories about the college and school.

While speaking about the support systems, 'C' is very grateful to her parents. The parents are struggling hard to take care of her. The financial condition of the family is not so stable to spend Rs 30000 on treatment every month. The family had a car and an autorickshaw previously. But they had to sell an acre of land and the vehicles for the treatment purposes. Though the father can get jobs in places far from home, he cannot opt for them since the child is sick. Also, the mother has to be with the child always and unable to go for jobs. Sometimes 'C' thinks that she is a burden for the entire family since a lot of money has to be spent on her. The support of the sibling is also noteworthy. The bond between the siblings is so strong that they cannot live apart. The sister of 'C' helps her in all the needs like the mother. The support of the family and the cousins were also the strength of 'C'.

The economic costs of the disease are very much expensive. Even the cooperative bank charges around Rs 3000 during the visits. Apart from this, the family spends Rs 30000

every moth for the medicines and tests. The charge for the cab would amount up to Rs 6000. To meet the financial needs, the family depends on the benevolence of people around them. Many people have donated money and materials for the welfare of the family. A few furniture and utensils of the family were donated by people to help 'C' in her sickness. Though the family has the health card, it is not accepted in the private hospitals. The private insurance companies are not ready to provide insurances. The family is not aware of any schemes of the government.

The future aspirations of 'C' is to secure a job or go abroad and make her parents happy. She also wishes to contribute to the society in her own way. She believes that there would be a day when she is able to build a better house for the family. The family is in need of digging a borewell to meet the daily needs. The family now spends Rs 1500 every month on water.

4.5 Case 'D'

Case 'D' is an eighteen year old young girl hailing from a lower middle class family in a rural area in the district of Pathanamthitta, Kerala.

The family consists of 'D', her father and mother. 'D' lost her younger sister few months back. She had a heavy bleeding, low BP and HB. At the time of death, she was 15 years old and was in the tenth standard in the school. 'D' has completed her plus two studies from a nearby school run by private management. After the studies, she joined a six month course on digital marketing. However, she could not complete the course as she lost her sister accidentally. Since she could not obtain the certificate, the studies did not help her find job. At present, she works from home in the call centre of Jio telecom company. Her father runs a small shop near to the house. During the day time, he works in the rubber plantation for daily wage. After the work, he goes to the shop. Her mother is a housewife. However, she helps the father in the shop till noon. Few years before, she used to work as part of the MGNREGA scheme of the government. But now, she cannot do this since she has to take care of her daughter. 'D' was diagnosed with SLE while she was studying in the fourth standard. She was then 9 years old. She got paralysed below the waist at 12. At present, she gets the treatment from a private hospital in Kochi, Kerala. The interested hobbies of 'D' are reading, painting, spending time meaningfully in phone. Her paintings were beautiful and the anganwadi teachers

and some neighbours brought home the pictures. She faces difficulties to draw now since she has pain while holding the brush for long. Moreover, she cannot sit for long since she will develop pain on legs.

During the final examinations in the fourth standard, she developed symptoms of SLE. Rashes began to appear on the face as well as hands. The parents took notice of the changes and consulted a dermatologist in Pathanamthitta. Though she was provided with medicines, there were no changes in the body. After few months, she was taken to a government hospital in Kottayam. After a week of admission and tests, the doctors diagnosed SLE. Since at that time, no hospitals in Kerala were competent to treat SLE, she was referred to a hospital in Mumbai. She was admitted in a hospital in Mumbai for three months. After three months, the doctors prescribed few medicines and referred 'D' to a private hospital in Kochi, Kerala. The treatment continued without much complications for another three years. While she was at 12 years of age, she had severe pain on legs. She could not even fold her legs to an extent. Thus, she was taken to a hospital where she was required to do the MRI scanning. Since the cost of scanning was unbearable, the family moved to a government hospital in Kottayam. She was admitted there for two months. It was during this treatment, something tragic happened to her. She lost the movements of legs. She had paraplegia, paralysis under the waist. No medications could recover her. However, the treatment continued there for another five years. The doctors there referred to a new hospital in Kochi, especially specialized in rheumatology. The hospital was then quite known for the quality treatment. The family heard the success story of a patient with SLE who underwent treatment from that hospital.

The symptoms associated with SLE were fatigue, headache, mouth ulcers, mouth infections, black spots on the finger nails, hair loss, skin allergies etc. The pain came to the picture in the second phase of the disease. Exposure to the sunlight would severe the pain and produce burning sensations. The three years following the diagnosis went without any complications. But after three years, when the symptoms reappeared, it became difficult for 'D' to engage in any daily activities. She could not walk, run, climb stairs etc. Due to this, she had to cut short the school attendance, into two days in a week. She was taken to the hospital in an autorickshaw. The school authorities had provided a wheelchair for free which helped her access the class rooms. She needed the help of her mother and sister to do her own personal tasks. Moreover, she lost the

eyesight of her right eye two years back while she was undergoing the treatment. She was taken to a hospital in Thirunelveli to treat the eyes. The doctors there assured that the sight could be regained it proper treatment is given. At present, 'D' is having leg pain which is actually a good sign. Actually, she had lost all the body movements under the waist along with the paralysis. Sensing pain on the leg would mean that the blood started circulating once again.

The fatigue associated with the disease posed a threat. At school, the fatigue issues prevented her from playing games, attending school assemblies and going out freely with friends. When she experienced fatigue, she tried to cope up with it by sleeping. There were feelings like something is happening with head and chest. She feels lazy to do anything creative or keep herself engaged.

As of now, the treatment consists of monthly hospital visits, injections, medications etc. She is required to take eight tablets a day. 'D' is confident that the medications have no side effects. However, she shared that the steroids have caused obesity issues. Though there is pain on leg, doctors have not yet given any painkiller as the pain would help her regain the movements of the leg. At hospital, she has received education on an average level about the disease. Since the information was not complete, she searched in the internet to see the disease and its nuances. She has not yet received any counselling services to cope up with the psychological traumas associated with the disease. The approach and the attitudes of the doctors and nurses were helping her to regain herself.

Because of the disease, 'D' had to go through many psychological traumas. Initially she had issues, but later, as she became paralysed and lost eyesight, she experienced mood swings, fear, anger issues, habit of crying frequently, lack of confidence. However, she has gained resilience and accepted her disease condition. Usually, she keeps her pain for herself. She does not disclose her difficulties to parents or anyone. She does not cry or reveal her pain in front of her parents as she thinks that this would make them sad. She lost her happiness and internal peace with the death of her sister. It was an unexpected death. It was her father who first communicated the message to her. She was the last one to hear about her sister's death. Soon after the death, the neighbours, friends etc started flowing into the home to ease her. However, she could not accept the fact that her sister died. She felt depressed and had suicidal ideations. She wanted to

end her life. There were many medicines on the table in front of her. In fact, she took a medicine. While she was attempting to have the other medicines, the people around her prevented her from doing this since they felt something wrong. Up until now, she has not disclosed this to her parents. She thinks that her life is a burden to her parents and all. Though financially unstable, they had to spend lakhs of rupees for her treatment. One day, when she experienced severe pain and cried, she saw her father and mother sitting on the bed crying. This was a sad sight for her. On that day, she took a decision that she would not make her parents sad. Even though she cries, it would be in the nights when the parents are on their bed. The friends offered her good company in the days of trouble. She also has doubts and tensions when thinking of the future. She almost has lost her dreams and energy to dream high.

'D' experienced difficulty in accepting the fact of hair loss. Each time she had to cut hair, she did it with utmost pain. Gaining weight was also not easy to accept. As she lost eyesight and body movements, she almost lost herself. It was difficult for her to face the realities of life.

What helped her move on with courage was the support extended by the friends. There are friends who often visit and spend time with her. Some of her friendships are lasting for the past fourteen years. The help from the religious circles always strengthened the family. The priest of her church has taken sufficient care to accommodate her into the services. He assures her presence in the major festivals. The youth association of the church pay frequent visits to the house of 'D' and gives her a good company. The shop is running in one of the buildings owned by the church and no rent is charged for the building. Moreover, the church which is not so rich has managed to assist the family in meeting the treatment expenses of both the daughters. The attitude of the people towards 'D' was always healthy. Everyone in the neighbourhood knows the details of the disease of 'D'. People are always supportive and they help the family either by helping them financially or offering mental support. The support of the friends in the school helped her to complete the school education successfully. Whenever she reached school, the friends reach to the gate and help her by carrying the bag, pulling the wheel chair etc. The teachers were also helpful in all aspects. Teachers took her to all the labs and facilities provided by the school. All the relatives support the family in all its needs. The support from the panchayath administration was less. There were lots of difficulties

in getting the disability certificate. However, the support of the health department is appreciative. They visit ‘D’ every month.

Being financially backward, the family struggled a lot to meet the treatment expenses. Up until now, the family spent around fifty lakhs on the treatment of ‘D’. Since the major portion of the treatment was done in the private hospitals, treatment expenses were higher. Also, the medicines prescribed were costly. The family spends Rs 20000 every month on an average. The family has a huge amount of debt in bank and private financiers. The only source of income of the family is the daily wage of the father and the meagre income from the shop. The family has no insurances. The govt insurance is not recognized by the private hospitals.

The friendship of ‘D’ with ‘C’ was very helpful in coping up with the disease. She feels her as her own sister. They mutually share their health concerns, joys and sorrows. They came into contact through a television program that pictured the details of ‘C’.

‘D’ aspires to get a good job in the near future through which she can help the entire family. Her area of interest in computer related jobs. She had scored 92% marks in the plus two examinations. She has no clear cut idea about what course to be continued. She is preparing for the PSC examinations gradually. While speaking, she also expressed her desire to be part of the support group specifically meant for the SLE affected people. She believes that such a group would benefit her to get motivated from each other, clarify the doubts, clear the misconceptions and support each other. As of now, ‘D’ does not know any children affected with SLE except ‘C’. Since she found that the friendship with ‘C’ helped her a lot, she is hopeful that such a group would give her lots of friends who would support each other. She is also aspiring to develop her skills in painting.

4.6 Case ‘E’

Case ‘E’ is a seventeen-year-old young girl hailing from a mountainous region in Kerala. She belongs to middle class family. She lives with her father, mother, elder brother and grandmother. Agriculture is the only source of livelihood of the family. Cardamom and pepper are the chief cultivated crops. The father is a farmer and her mother is a housewife. Her elder brother has successfully completed the plus two examinations and is preparing for the higher studies. The grandmother is aged 78 and

she is physically fit. ‘E’ is doing her plus two studies from a nearby private school. She was diagnosed with SLE last year, in the month of August when she was 16 years old. At present, ‘E’ is in treatment from an Ayurvedic hospital. The interested hobbies of ‘E’ are athletics. She was an active member of NCC before the onset of the disease. She had to stop participating in the athletics competitions owing to severe pain on legs. She also could not continue with NCC for long since exposure to the sunlight was harmful for her. Moreover, the doctors had advised to refrain from any activity that involves exposure to the sunlight.

The journey with SLE starts in ‘E’ at the age of thirteen. The primary symptoms of SLE in ‘E’ were sneezing and butterfly rashes on the skin when exposed to sunlight. The parents did not take them seriously since they thought that it would be the result of any hormonal variations. ‘E’ used to complain frequently that she is experiencing severe pain on legs. She had to walk quite a long distance to catch the bus to school. The pain was so severe that she could not place even a single step. Moreover, the sneezing was beyond control. Later, she developed severe body and joint pain. Headache was also constant. Thus, she was taken to a primary health centre nearby. After the initial round of blood tests, it was found that the number of platelets is far below. Thus, the doctors referred her to a govt medical college. Medicines were given to increase the number of platelets. Though there would be a sudden increase in the amount, it would quickly go down. Since the doctors could not identify the root cause, they referred her to a private hospital in Kochi. After a series of medical examinations, she was diagnosed with SLE. Doctors advised admission in the hospital. But since it was impossible for the family for many reasons, both financial and practical, they preferred treatment in a popular private hospital which is not that far from their native place. She was under the treatment in the hospital for the next six months. ‘E’ was prescribed three injections which would cost Rs 40000 each. However, the injections did not reduce pain. She had severe breathing issues and pain on legs. Thus, it was difficult for her to walk even a short distance. The family accidentally came in touch with a govt ayurveda doctor. The family took her to the doctor and he guided the family to a well known ayurvedic doctor and retired professor. At present, she is under the treatment of this doctor. She missed many of her school days in the previous academic years. But the school management was so helpful and understanding that she did not lose much attendance. The principal who was a priest showed much empathy for the child. On many school days, when it

was found that ‘E’ could not sit in the and attend the class, the teachers brought her home in an autorickshaw accompanied by her brother and classmates. The auto charge was paid the school management only. The class where ‘E’ studies is located on the third floor. Thus, it was difficult for her to climb all the stairs. Though she manages to get there somehow, she develops breathing issues soon. She had difficulties even in getting down from the bus or scooter. It was her friends who helped her in her movements. She cannot stand for long since it pains. Lifting heavy things is not possible for her. However, she could do the personal duties like bathing, dressing etc herself. To help her avoid walking, the family bought a scooter and her brother used to drop her at the school. Meanwhile, the family enquired what treatment the other children are undergoing.

Fatigue issues have created troubles for ‘E’ very much. Every time, she feels to lay on bed. It is difficult for her to wake up in the morning and go to school due to fatigue. She feels a loss in energy in doing the activities of the day. She has developed laziness in doing the things.

‘E’ feels that the Ayurveda treatment has reduced her pain to a large extent. The treatment could somehow help her manage the symptoms. The joint pain still persists especially when waking up from bed. ‘E’ previously had migraine but the Ayurvedic medicines have reduced her headache. While she was under the treatment in allopathy, she was prescribed many steroids which had many side effects. Thus, she had gained weight. After starting treatment in Ayurveda, the family and the patient are confident and hopeful that health could be recovered. Moreover, the treatment expenses are very low. The monthly expenses would amount up to Rs 3000. But while she under allopathic treatment, the family spent Rs 20000 on an average every month. Also, the ayurvedic medicines do not have side effects. As part of treatment, ‘E’ is required to limit the non-vegetarian and oily food and take food with coconut mix. ‘E’ shared that she had got only basic information about the disease. The hospitals or the doctors did not provide any counselling services.

‘E’ shared that she has not faced any issues of loneliness in her life, especially after the onset of the disease. Her friends used to support her in all her needs. She is bold and has the courage to face the challenges of the disease. She has difficulties in accepting her body image. The obesity makes her less confident and moreover, the people around

are more suspicious about the obesity of ‘E’. The society sees the obesity as the result of her laziness. So, many times, the parents were advised to keep the children engaged in the household chores. People around are not able to accept the body image of ‘E’. However, she has accepted her bodily changes.

The friends, teachers, relatives were her sources of support throughout the years. Though she missed many school days, she faced no difficulties since the friends either teach her or send her the notes. The class teacher knew the condition of ‘E’ well and thus her well-being was his concern as well. Though she was absent for many days, it did not affect the academic life. the management was so friendly that they were ready to do whatever possible for her. The principal of the school who is a priest took a special care in the case of ‘E’. he had assigned the students to carry the bag of ‘E’ when she comes school and help her out in reaching the class. He sanctioned the medical leaves without creating problems. Special help was provided to help her write exams. Whenever she felt pain, the management was ready to help her reach home. She experienced support from her religion as well. Though it was compulsory for the children to attend the Sunday catechism classes, she had special consideration. In her church, the children were supposed to go to church on every Saturday morning. In this case also, ‘E’ had exceptions. Also, the parish priest had arranged a special chair for ‘E’ to sit as she cannot stand for a long time during the religious services in the church. However, few people like the headmaster of the catechism are not able to understand the difficulties faced by ‘E’. They are more demanding than accepting. This may be due to the fact that they are ignorant of the disease conditions. Through the support of the friends and the teachers, ‘E’ managed to score good marks in the final exams. The love and concern of the parents as well as the cousins were extremely great. The family has not yet revealed the details of the disease to the people around their locality. The family feels that the society around them are fast to make judgements and criticisms. They often do not try to understand the root causes. Instead, they are very much bothered about what is going on in the family of others.

The economic costs of the disease is bearable now as they have turned to ayurveda now. While the treatment was from private allopathic hospitals, they faced struggles to meet the both ends of the family. Since the family has to send the elder son for higher studies, the family fears how they would find money for ‘E’. Altogether, the family has spent around three lakh rupees for the treatment alone.

The future aspiration of ‘E’ is to become a nurse. But now, she has worries about that dream. The family fears that nursing is not her cup of tea since she may not able to stand for a long time. Moreover, since she has taken commerce as her stream of study in plus one and two, the parents think that nursing would be little difficult for her.

4.7 Summary of the Chapter

The chapter presents the experiences of the participants diagnosed with Systemic Lupus Erythematosus (SLE). The experiences include the participants’ road to diagnosis, medical history, symptoms and other physical challenges, psychological, social, economic challenges. The chapter also include the narratives regarding the various supporting systems and the coping strategies used by the participants to manage the challenges.

CHAPTER FIVE: THEMATIC ANALYSIS AND DISCUSSIONS

Chapter Five: Thematic Analysis and Discussions

5.1 Overview of the Chapter

The process of moving from the primary data that has been gathered as part of the research study and using it to offer explanations, understanding, and interpretation of the events, people, and situation that we are researching is known as qualitative data analysis. The focus of thematic analysis is on identifying, assessing, and documenting patterns or themes within the data that is accessible.

In this part, the researcher has laid more focus on presenting and analysing the lived experiences of the children with SLE without losing its logic, continuity, significance and inherent beauty. In other words, the story has to be said in its original tone. The researcher felt that a strict adherence to the objective wise analysis would make the analysis and the interpretation less obvious and moreover, it may affect the logical continuity of the study. For this purpose, the researcher felt it good to mix the themes in the analysis. The kind of analysis that is used be the researcher here helps to better understand the lived experiences of the children with SLE.

The themes used in the analysis include medical history, side effects of medication, presenting and recurring symptoms, pain, fatigue, impact on ADL, emotional well-being, body image, relationship with peers and society, direct and indirect costs, support systems and the coping strategies.

5.2 Profile of Respondents

5.2.1: Personal profile of the children with SLE

(Table 1: Personal profile of the children with SLE)

Case	Age	Geographical location	Educational status	Type of School/College	Age at diagnosis
A	17	Rural	Plus two*	Private	16
B	18	Rural	BA Economics I*	Private	13
C	19	Rural	B.Com I*	Private	17

D	18	Rural	Plus Two	Private	9
E	17	Rural	Plus Two*	Private	13

The profile of the participants gives a basic idea about their age, educational qualifications, geographical settings and the type of educational institutions. The researcher conducted 5 case studies and all the samples belonged to the age group of 10-19. All the samples except '**D**' are pursuing their studies either in school or college, but with difficulty. In most of the cases, the diagnosis was not delayed. In the case of '**D**', she has been living with SLE for quite a long time and she had to stop education as the disease got severe. She had loss of eyesight during the treatment and paraplegia. It can be inferred from the data that living with SLE for a long period of time has adverse academic outcomes. The finding goes in line with the previous studies which state that school competence ratings were correlated with measures of cSLE disease activity and treatment intensity (Zelko, 2012). Also, all the participants are educating from private schools/colleges.

5.2.2 Profile of the parents

(Table 2: Profile of the parents)

Case	Parents	Occupation	Financial Status
A	Father, Mother	Business, Housewife	Upper
B	Father (late), Mother	Govt. Hospital attendant (Contract)	Middle
C	Father, Mother	Daily wage, House wife	Lower
D	Father, Mother	Daily Wage, Housewife	Lower
E	Father, Mother	Farmer, Housewife	Lower

The above table gives basic information about the parents, who are the caregivers of the children with SLE. All the cases except '**B**' have both the parents. '**B**' had lost her father eight years back due to a heart failure. Except '**A**', all the other cases are financially backward and thus would find it hard to meet the expenses of the treatment. The father of '**A**' is a businessman who has a better annual income. In almost all the families, the father alone is the breadwinner of the families. While the fathers of the children are out for work, the mothers assume the role of the caregiver. While the mother of '**B**' is a salaried employee, the parents of '**A**', '**C**', '**D**' and '**E**' are working

in unorganized sector. Working in the unorganized sector adds on the burden of the SLE in the children.

5.3 Discussions

Research Question: What are the challenges and coping strategies of the children with SLE?

Theme 1: The road to diagnosis

Here, the researcher attempts to draw from the data, the information concerning the medication and treatment, medical history, side effects or complications associated with the medication, availability of the complementary and alternative health services for the children with SLE.

Subtheme 1: Medical history

Undoubtedly, living with SLE has been a bitter experience for all participants of the study. One among the significant factors responsible for the severity of the disease activity and the flares is the delayed diagnosis. As the article, "Systemic Lupus Erythematosus in India" points out, the low survival rates of SLE in India can be traced back to reasons like delays in diagnosis (Malaviya, 1997). Very often, the delayed diagnosis take place because of the failure of the parents to take the symptoms seriously. In all the cases, the families had to move through different hospitals to get the right diagnosis. At times, few hospitals failed in diagnosis and had made wrong medical advice. This has caused adverse health impacts on the children with SLE and their families. In the case of '**B**', she was advised amputation of the leg which was based on a wrong diagnosis. The article highlights that referral bias that exists in the hospitals of India prevent the children with SLE from reaching the major city hospitals (Malaviya, 1997).

It has been found from the data that the participants receive treatment from different systems of medicine. All the cases are undergoing treatment in hospitals managed by private sector. Thus, the treatment expenses for all the respondents are quite higher. All the participants reported that they have gained a better health through the treatment

Case A: The parents of '**A**' had failed to take note of the symptoms. It was a relative of '**A**' who felt something wrong and advised medical consultations. To reach the right diagnosis, the family had to go to different hospitals which include a clinic in the neighbourhood, government hospital at the taluk level, a private hospital in Changanacherry and the private hospital in Kochi where the SLE was diagnosed. Since the treatment was costlier and the hospital is far, the family shifted the treatment to the private hospital in Kottayam where '**A**' is undergoing treatment now. In her case, the diagnosis took place without much delay. The treatment in the hospital is quite satisfactory. In the initial phase, '**A**' had to make monthly visits, but now she visits the doctor once in two months.

Case B: '**B**' was late in identifying the symptoms and its seriousness. She got pain on legs. When the pain was unbearable, she was taken to a private hospital in Kottayam. The medicines prescribed could not subside the pain. The doctors advised amputation of the leg. The family was completely dissatisfied with the treatment provided by the hospital. Since the treatment was not satisfactory, the family moved to a private Ayurveda hospital. Since the pain did not get subsided, she was led to a well known hospital in Madurai. After several medical tests, she was diagnosed with SLE there. Later, they shifted to a popular private hospital in Kochi for the further treatment for practical reasons. She was given proper medications and she began to regain the quality of life. Three years later, as '**B**' failed to take medicines in the prescribed manner, she began to develop rather worse symptoms. The bleeding associated with menstruation prolonged for many days. This time, she sought the treatment from a gynaecologist. Since the amount of haemoglobin went below the required level, she was once again referred to the private hospital in Kochi. She needed blood transfusion immediately. For practical reasons and as the doctors permitted, the family moved to the private hospital in Kottayam. The condition got aggravated in this hospital since she was given only one bottle of blood. She lost the eyesight of the right eye completely. She had huge swellings on both the legs. Later, she had to be referred back to the private hospital in Kochi. By this time, SLE had affected many organs. But the proper medications helped her regain health. At present, she undergoes the treatment from this hospital. She goes hospital once in two months. Initially, she was supposed to take 13 tablets after the breakfast every day. The doctors have now reduced the dosage and frequency of hospital visits.

Case C: It took a long period of time to diagnose SLE in '**C**'. She was initially taken to a neighbouring clinic. Since more symptoms began to develop, she was guided to a private hospital in Idukki. After the blood tests, she was referred to the government medical college hospital in Kottayam where she was diagnosed with SLE. Since there was no treatment for SLE there, the family moved to a private hospital in Thiruvalla. The doctors have concluded that '**C**' has developed MCTD (Mixed Connective Tissue Disease). Until now, '**C**' was admitted in the hospital six times. She goes to the hospital every month now. Whenever the pain gets aggravated, '**C**' visits the nearby cooperative hospital in Kattapana. The pain becomes severe when the climate is extremely cold. Since '**C**' lives in a monsoon area, she falls to severe pain frequently.

Case D: Noticing the changes in the skin, '**D**' was taken to a dermatologist in Pathanamthitta. Since there were no changes, she was taken to the government medical college hospital in Kottayam, where she was diagnosed with SLE after a number of medical tests. Since no hospitals in Kerala were competent to treat SLE, she was referred to a private hospital in Mumbai. After three months of admission, the doctors referred her to a private hospital in Kochi. There were no complications for three years. Later when pain developed on legs, she was taken to a private hospital in Thiruvalla where it was required to do the MRI scanning. She then moved to the government medical college hospital in Kottayam. She had paraplegia during the treatment. After five years of treatment, she was referred to a new private hospital in Kochi which is specialised in Rheumatology. As of now, the treatment consists of monthly hospital visits, injections, medications etc. She is required to take eight tablets a day. There are some good signs on her leg which had gone paralysed. She started developing pain on legs.

Case '**E'**: After the development of symptoms, '**E'** was taken first to the primary health centre. As the number of platelets in blood went below the required volume and no medications could control, she was referred to the government medical college hospital in Kottayam. The doctors referred her to a private hospital in Kochi for the further treatments. In the hospital, she was diagnosed with SLE. Though doctors advised admission for several days, the family could not afford it. Thus, they shifted her to a private hospital in Kottayam. She was under treatment in the hospital for six months. Since the pain was not subsided, she was taken to a private ayurveda hospital. '**E'** feels

that Ayurveda treatment has reduced her pain to a great extent. The treatment could help her manage the symptoms.

In the cases of '**A'**, '**B'**, '**C'**, and '**E'**, the parents failed to address the symptoms with seriousness. It is found that there is a relation between the delay in diagnosis and disease activity and impact. In '**C'**, the diagnosis got delayed and she developed severe SLE. This finding is in parallel with the observation that the interaction of several factors might result in diagnostic delays that worsen disease activity, damage multiple organs, raise the likelihood of hospitalisation, and require severe treatment (Hussain, 2022). The following table provides information about the months/years taken for the diagnosis:

(Table 3: Months/year taken for diagnosis)

Case	**Months/Year Taken for Diagnosis**
A	Six Months
B	Five Months
C	Four Years
D	Eight Months
E	Seven Months

It has been found from the data that all the participants except '**E'** receive treatment from allopathic systems of medicine. '**E'** had her treatment initially from allopathy, but now she undergoes treatment in Ayurveda system of medicine. '**E'** feels that she has become better and there are no side effects for the medicines. Also, the treatment costs are much lower. All the participants are undergoing treatment in private hospitals. Each participant had to go through at least three hospitals before the diagnosis. This points to the failure of the hospitals to identify the disease condition. The wrong diagnosis had in fact caused severe damages in the participants. In certain cases, the parents consult the specialized doctors. For example, when there was hair loss, the parents of '**D'** took her to a dermatologist. The following table gives the details of the different hospitals the participants consulted, the system of medicine and the type of the hospital.

(Table 4: Hospital History)

Cases	No of hospitals consulted before the diagnosis	The system of medicine (Currently)	Type of hospital (Private or government)
A	5	Allopathy	Private
B	6	Allopathy	Private
C	5	Allopathy	Private
D	7	Allopathy	Private
E	5	Ayurveda	Private

Subtheme 2: Side effects associated with the medication and treatment

The treatment and medications have significant side effects on the physical and psychological wellbeing of the participants. Except '**E'** who is undergoing treatment in Ayurveda system of medicine, all other participants experienced side effects like obesity, mood swings etc. Though the medicines are able to manage the symptoms, the participants find it difficult to accept the complications. The findings correlate with the studies that say that the most often expressed concerns-worries about look and weight-were frequently connected to steroid use (Hale, 2014). '**B'** and '**C'** shared that the failure to take the medicines at proper time caused disease flares. To reduce the complications of the medications like obesity, it is found that '**B'** had made certain lifestyle changes like control on the diet. Through this, she was found to be able to decrease the body weight.

Case 'A': To manage the symptoms, the doctors had prescribed steroids. While narrating the side effects of the steroids, '**A'** said: "*Yes, the medicines have reduced my pain to a great extent. But in the process, I have lost myself. My weight increased rapidly because of the medicines from 33 kg to 57 kg".* She had loss of appetite, mood swings and loss of appetite as a result of the medications. This restates the observation that the disease's treatment with steroids or another drug can be responsible for the depressive symptoms of the children with SLE (Giffords, 2003). She also has fears about her height. She fears that the medications would prevent her growth in height.

Case 'B': '**B'** feels that the medicines provided by certain hospital were not able to subside her pain on the legs. The failure from her part to take the medicines without fail have caused her severe damage to health.

Case 'C': Since '**C'** is taking steroids, it has got side effects like swelling. If she misses medicine, she develops severe pain and the entire treatment process gets complicated.

Case 'D': '**D'** is confident that the medications have no complications. However, she shared that the steroids have caused obesity issues.

Case 'E': While '**E'** was under the allopathic treatment, she had taken steroids which added on her weight.

Pattern matching

(Table 5: Pattern Matching)

Case	Side Effects of Medications (Common)	Side Effects of Medicine (Uncommon)
A	Obesity	Loss of appetite, mood swings
B	Obesity	failure to take medicine caused severe damage
C	Obesity	severe pain if there is failure to take medicine
D	Obesity	Mood swings
E	Obesity	

Subtheme 3: Coping with the complications of medication

While tracing the coping strategies used by the participants for managing the difficulties associated with the drugs, the researcher could identify the following. All the participants were seen to be convinced of the ill effects of the medication. Thus, each case has her own strategies. Learning that the drugs would prevent from gaining more height, '**A'** brought home a horizontal bar to help her increase height. Case '**B'**, understanding that the drugs would cause obesity stopped taking medicines and started diet on her own. This had unintended results. Case '**C'** also has skipped medicines to prevent obesity. Case '**E'** shifted to Ayurveda as an attempt to lessen the side effects.

While analysing the effectiveness of the coping strategies, it becomes clear that while certain strategies were almost befitting, others were certainly not.

(Table 6: Coping strategies to manage drug complications)

Case	Coping Strategies	Effectiveness
A	Bought horizontal bar to exercise	No
B	Stopped medicine, diet	Diet was successful
C	Stopped medicine	No
D		
E	Shifted to Ayurveda	Yes

Subtheme 4: Complementary and alternative health services

The responses under this theme are mixed. While '**A'**, '**B'** and '**E'** report that they have not received the health education as they expected, '**C'** and '**D'** are satisfied. However, all the respondents feel that they need additional information on the disease. All the respondents except '**C'** state that they have not been provided with counselling services. All the participants had referred to google to find out the features of their disease condition. It is found that this often misleads them and they develop fears about their disease condition.

Case 'A': '**A'** was of the opinion that the healthcare professionals should disclose the information about the disease conditions to the patient as well. Many times, she felt that the doctors disclose the details to the parents and not to her. '**A'** has got various doubts regarding the disease. Thus, she feels that the doctors should provide health education as well as counselling.

Case 'B': In her experience, only few hospitals have provided her with the necessary information about the disease. She felt that few doctors were insensitive to the symptoms. At the same time, few doctors comforted her and gave her emotional support.

Case 'C': Apart from treatment, '**C'** feels that the healthcare professionals had offered counselling and health education. '**C'** feels that the doctors have not disclosed all matters to her. She says, "*When my mother was in tears, I have seen the doctors comforting her saying that she shall not cry in front of me".*

Case 'D': '**D'** is of the opinion that she has received education on an average level about the disease. She has not yet received any counselling services to cope up with the psychological traumas associated with the disease. In her experience, the approach and the attitudes of the doctors and nurses were helping her to regain herself.

Case 'E': '**E'** shared that she had received only basic information about the disease from the hospital. Also, the healthcare professionals have not provided any counselling services.

Subtheme 5: Coping strategies to manage health education

(Table 7: Coping strategies to manage health education)

Case	Managing Health Education
A	Google
B	Google
C	Google, Health care professionals
D	Health Care Professionals, Google
E	Google

From the above table, it becomes clear that Google is a major source of reference for almost all the participants. However, their doubts persist even after this. Moreover, it was found that the children are often misguided by wrong disease related information. Thus, it fails to be an effective strategy.

Theme Two: Physical challenges

Here the researcher tries to point out the physical challenges associated with the onset of the SLE in the children. Based on the data collected from the five samples, it can be said that all the cases had different symptoms. The impact of the disease also varied among the individuals. However, there are certain commonalities observed.

Subtheme 1: Presenting symptoms during diagnosis and recurring symptoms

While analysing the different presenting symptoms of the children with SLE, it becomes clear that certain symptoms are common. As the studies elucidate, the common symptoms found are skin rashes, leg pain, head ache, swelling, hair loss etc

(Ozel, 2015). These symptoms may not appear together in children, but rather, it begins with any of these. For '**A'**, '**B'**, '**C'** and '**D'**, it started with rashes either on face or legs. In the case of '**E'**, it started with sneezing. As it is already made clear, the caregivers may not take these seriously since these symptoms are very common for many ordinary diseases. These are non-specific symptoms. This finding resembles very much with the notion that the reason why Lupus becomes difficult to diagnose is that the symptoms are very much varied in the individuals. Other ailments can also exhibit the similar symptoms (Giffords, 2003).

Case A: "*I saw some rashes on my skin before I was diagnosed with SLE. After two or three days, the red rashes turn into black colour, later the rashes disappear. After that, there was severe hair loss.*" In the narrative of the parents, '**A'** experienced severe pain on legs and headache. The parents did not consider the symptoms seriously. It took around six months to diagnose the disease. SLE was diagnosed at the fourth hospital only.

Case B: The symptoms in '**B'** were in the form of black rashes on the right leg. She delayed visiting hospital until the pain became acute and spread to the other leg and hands. '**B'** had to go through four hospitals for the right diagnosis. Thus, the diagnosis got delayed.

Case C: The symptoms started with hair loss accompanied by severe headache, swelling on face, vomiting, eye pain and dizziness. Later she developed severe pain on legs and butterfly rashes. "*I used to faint in the class many times. Those times, my parents used to get frequent phone calls from the school that I have fainted down. The teachers wanted me to consult a doctor soon".* Though the symptoms started appearing when she was 13, she was diagnosed with SLE only at 17.

Case D: SLE manifested primarily in the forms of rashes on face and hands. It took several months for the final diagnosis. Later she developed severe leg pain.

Case E: '**E'** developed symptoms like sneezing, butterfly rashes, severe pain on legs, acute pain on joints and headache. At first, when there were rashes, parents thought it as the result of some hormonal variations. The interval period between the symptoms and the diagnosis was seven months.

Pattern matching and rival explanations

(Table 8: pattern matching and rival explanations)

Case	Common Symptoms	Other Symptoms	Rival Explanation
A	Rashes on skin, leg pain, head ache, Swelling	hair loss	Hair loss (alopecia) occurs in SLE due to factors like disease activity, medications, differences in immune response.
B	Black rashes, leg pain		
C	severe headache, leg pain, butterfly rashes, swelling on face, black rashes	vomiting, eye pain, dizziness	The SLE in 'C' is severe. Doctors have diagnosed her with MCTD (Mixed Connective Tissue Disorder)
D	Rashes, Leg Pain, headache,	Mouth ulcers, black spots on the nails, hair loss, Skin allergies	The uncommon symptoms in 'D' can be due to medication and other immunological factors
E	butterfly rashes, severe pain on legs, acute pain on joints and headache	Sneezing	The sneezing in 'E' can be due to medication and other immunological factors

Apart from the presenting symptoms, the participants are faced with few other physical challenges which recur in them causing significant impairments. These challenges

persist even though treatment is given. Each case experienced different recurring physical challenges. Leg pain, joint pain and swelling are commonly seen recurring symptoms. Loss of memory, episodes of seizures, hallucinations that is seen in '**A'** and '**B'** are also attested by the literature reviewed (Levy, 2012). The differences can be due to immunological factors, medication and disease activity. The following table gives the details of the recurring physical challenges.

(Table 9: Recurring Symptoms)

Case	Recurring Symptoms
A	Leg pain, joint pain, Pain on neck
B	huge swelling on both the legs, lost the eyesight of the right for three years, had memory loss, episodes of seizure, severe bleeding, no menstruation, impossible to conceive.
C	Extreme pain in winter, swellings on finger, joint pain
D	Severe joint pain, burning sensation in sunlight, severe leg pain, paraplegia, lost eye sight
E	Severe leg pain, breathing issues

Subtheme 2: Coping strategies to manage pain

Since pain is one among the significant concomitants of SLE, all the participants are to manage pain or cope up with pain in their own way. Each participant has developed her own strategies for coping. Most of the coping strategies used by the participants fail in the realization of the purpose. '**A'** prefers sleeping or laying on bed as a means to forget pain. Also, she depends on her mother to get her body massaged. '**B'** also was found to be relying on sleeping to get rid of the severe pain. She also shows some strange behaviours like undressing herself, crying aloud to decrease the intensity of the pain. '**C'** depends on her mother for massaging when faced with severe pain. Though she tries to sleep, it does not work well with her. Like '**B'** she also cries aloud. It was found that '**E'** relied mostly on sleeping to ignore the pain. From the responses of the participants, it was clear that no strategies were successful in managing pain.

(Table 10: Coping strategies to manage pain)

Case	Coping Strategies to Manage Pain

A	Laying on bed, massage
B	Sleeping
C	Massaging
D	Sleeping
E	Sleeping

Subtheme 3: Disease impact

While analysing the disease impact, it becomes clear that '**B'**, '**C'** and '**D'** are severely impacted by the disease. Though the condition of '**B'** is stable now, she had previously experienced difficulties in performing the Activities of Daily Living (ADL). All the participants are affected and face restrictions in performing the ADL. The association between SLE and impairments in ADL are well brought out by the studies. As the studies rightly point out, in patients with SLE, hand involvement is one of the major contributors to reduced function in daily living activities (ADLs), home chores, productivity and absenteeism, and health-related quality of life (Keramiotou, 2021). Apart from this, the disease conditions of '**C'** and '**D'** are so severe that they cannot even do their own personal tasks. This has actually resulted in the school absenteeism of the children as well as the workplace absenteeism of the caregivers. This is detailed in the section where the indirect costs of SLE are discussed. The timely support provided by different support systems have facilitated the children to perform the activities. (For example, the friends, teachers, school management, religious leaders etc rendered support to ease the daily life of the children with SLE). The differences in the disease impact on ADL (Activities of Daily Living) are due to various reasons like immunological, genetic, disease activity, environmental factors etc.

Case 'A': The symptoms made it extremely difficult for her to engage in any kind of physical activities. The situation has become better after the medications. She faced troubles in walking, running, participating in sports activities, lifting heavy things, doing the household chores. She could manage her personal tasks by herself. She had to stop enjoying badminton, dancing, cycling and reading which she was so fond of before the symptoms had appeared. The pain on the neck prevents her from carrying bags. Also, it has become difficult for her to attend the classes with proper concentration.

Case B: As part of SLE, '**B'** experienced severe pain on legs. The pain was so acute that she could not even walk a step. As a result, she had to stop going to school for months. She developed huge swelling on both the legs, lost the eyesight of the right for three years, had memory loss, episodes of seizure etc. She also found it difficult to engage in physical activities like walking, running, sports, exercise, lifting heavy things, taking bath etc. Out of the severity of the pain, '**B'** cries aloud, tries to undress herself and tries to get out of the bed. She has severe back and head ache. '**B'** said: "*I had severe bleeding for three months. I could not even move out to anywhere as I was afraid of bleeding. During that time, I used to take tuition classes in the evening. But I had to stop it. For the last six months, I am not having menstruation. The doctors say that I cannot conceive"*

Case C: '**C'** often gets extreme pain especially when the climate is cold. Since she lives in the high ranges of Kerala, the climate is often cold there. When there is pain, '**C'** is unable to any activities of the daily life. she cannot even walk or lift her legs to climb the stairs. She finds it impossible to bath by herself or wash her clothes. She is not able to lift anything when there is pain. She cannot even drink a glass of water by herself. Even fingers start swelling. She can't feed herself or fold the hands and legs. '**C'** said: "*One day, I was admitted in the hospital. On a night, I got severe pain and started swelling all over the body. Suddenly, I could feel that my dress began to tear".*

Case D: '**D'** experiences joint pain in its severity. Exposure to the sunlight began to severe the pain and produced burning sensations. It was difficult for her to engage in physical activities like walking, running, climbing stairs etc. She needed the help of her mother to do her own personal tasks. While she was under the treatment, she had severe pain on legs and she could not even fold the legs. Later she had paraplegia (paralysis under the waist). She also lost the eyesight of her right eye.

Case 'E': SLE has caused severe leg pain and breathing issues in '**E'**. It was difficult for her to walk even a short distance. On many school days, she had to skip the classes since she could not sit for long. She faced difficulties in climbing the stairs of the school. She had difficulties in getting down from bus or scooter. She cannot stand for long since it pains. Lifting heavy things is not possible for her. However, she can manage the personal tasks herself.

Pattern matching and rival explanation

(Table 11: Pattern matching and rival explanation)

Case	Disease Impact on ADL (Activities of Daily Living) in Common	Uncommon Disease Impact on ADL	Rival Explanation
A	troubles in walking, running, participating in sports activities, lifting heavy things, doing the household chores.	Inability to concentrate, carry school bags and engage in hobbies like dancing and reading	'A' has pain on neck which is why she cannot carry bags. Inability to engage in hobbies is the result of the fatigue associated with the disease.
B	Difficulty in walking, difficult to engage in physical activities like walking, running, sports, exercise, lifting heavy things,	Inability to go to school, Unable to take bath and do the personal tasks by herself	Usually, at the times of disease flares, the persons find it difficult to do the personal tasks.
C	cannot even walk, lift anything, engage in physical activities	Cannot climb the stairs, impossible to bath by herself or wash her clothes, cannot even hold a glass of water by herself. She can't feed herself or fold the hands and legs.	'C' is diagnosed with severe form of SLE (MCTD). The uncommon symptoms are due to this.
D	difficult for her to engage in physical activities like walking, running, climbing stairs,	cannot do the personal tasks by herself.	'D' had paraplegia as a disease impact.

E	Difficulties in walking, climbing the stairs, lift heavy things.	Difficulty in getting down from scooter or bus, cannot stand for long	The recurrent symptom in 'E' is the pain on legs.

Subtheme 4: Coping with impairments in activities of daily living

While analysing the responses of the participants, it became clear that the children and the families developed their own strategies to help children perform the activities of daily life. This was done either by providing external devices or by ensuring helping presence. In the case of '**A'**, her parents brought her a bicycle, yoga mat for helping her relax and do the exercises. Also, the presence of mother was there throughout the disease flares to help her. In the case of '**B'**, her friends and mother took an active role in helping her perform the personal tasks and taking her to school/college. In the case of '**C'**, her sibling sister collects water, mother helps in doing the personal tasks and other activities. The support of the school management also helped '**C'** to manage the impairments on ADL. A few well-wishers supported her by bringing a sofa, dining table, cot etc. In the case of '**D'**, the parents have bought a wheel chair. The mother assures her presence throughout the days to assist her. The school authorities have also purchased a wheel chair in the school exclusively meant for '**D'**. She received lots of support from her school friends who helped her in carrying the bags and pulling the wheel chair. In the case of '**E'**, the parents bought a scooter to help her in the transportation to school. The support of the school management and friends were remarkable. The principal of the school had entrusted the students with the responsibility to help '**E'**, in getting down from bus/scooter, carrying the bag, climbing the stairs etc.

The above mentioned coping strategies done by parents or others have helped the children perform the activities of daily life.

(Table 12: Coping strategies to manage impairments on ADL)

Case	Coping Strategies
A	Bicycle, Yoga Mat, *presence of mother*

B	*Presence of mother, sister, friends*.
C	*Presence of mother, sister, friends,* the well-wishers assisted her by purchase of furniture like sofa, dining table, cot and chairs
D	Wheel chair both in the house and the school
E	Purchased scooter, support of friends and the school management.

Subtheme 5: Fatigue and energy levels

All the respondents agreed that fatigue is the most common issue associated with SLE. There is a loss of energy in all the cases. Because of the fatigue, they find it very difficult to engage in physical activities. '**A'** is unable to take part actively in of the activities that were of interest to her before. Though she has an urge to do yoga or gym, the fatigue prevents her. She had started going for morning walks with her father, but had to stop due to fatigue. For '**B'**, the fatigue did not allow her to take part an active role in the house. She was found to be always lazy. '**C'** finds it hard to eat food while having fatigue. However, cases, '**C'** and '**B'** have accepted fatigue as part of SLE. Though there is a loss of energy, they have a determination to accomplish the various tasks. To help overcome the fatigue issues, '**A'** was advised by the healthcare professionals to get engaged in different occupations. However, she was unable to do those activities. Fatigue prevented '**D'** from playing games, attending school assemblies and going out freely with friends. She found herself lazy and less creative. From the analysis, it becomes clear that SLE is closely associated with fatigue and this is well brought out by the existing literature (Olesińska, 2018)

Case 'B': "*Even though I find it difficult to wake up from the bed due to the energy loss, I somehow manage to force myself to assist my mother in her household chores"*

Subtheme 6: Coping strategies to manage fatigue

'**A'** tried to manage her fatigue issues through strategies like riding bicycle, reading fictions, morning walk, spending time in mobile phone and social media and going to bed. However, it was found that none of them could help her manage fatigue. '**B'** tries to manage fatigue by sleeping always. '**C'** also tries to elude fatigue by sleeping, using mobile phones, etc. '**D'** tries to manage fatigue by sleeping, Likewise, '**E'** is also found to be using sleeping as a strategy to cope up with fatigue. However, none of these strategies work successfully.

(Table 13: Coping strategies to manage fatigue)

Case	Coping Strategies
A	Riding bicycle, reading, morning walk, mobile phone and social media, sleeping.
B	Sleeping
C	Sleeping, mobile phone
D	Sleeping
E	Sleeping

Theme Three: Psychological challenges

Here, the researcher tries to identify the psychological challenges faced by the children with SLE. The data is analysed to find out the emotional well-being of the children, self-esteem and issues with the body image of the children with SLE.

Subtheme 1: Emotional well-being

All the respondents faced some kinds of psychological challenges associated with the disease condition. '**A'** finds it terribly difficult to accept the disease. On the other hand, all the other respondents were able to accept their health condition. While analysing the data, it is found that most of the cases experience similar psychological challenges. It can be rightly said that SLE patients have a poor quality of life (Booth, 2018). The challenges that everyone feels are feelings of fear of death, hopelessness about the future, habit of crying and anger issues. '**B'** is unique in the sense that she never experienced tensions, suicidal ideations and isolation. She stood courageous in her pain and troubles. There are common features in '**B'** and '**E'**. '**E'** seems to be bold and courageous. '**C'**, though optimistic, has continuous mood swings like '**A'**. It is found that '**A'**, '**C'** and '**D'** exhibit mood swings, question their fate. They think that their life is a burden for the parents. '**C'** and '**D'** find it better to die soon. At the same time, '**A'** and '**D'** had attempted suicide.

The psychological challenges of '**A'** are quite different. She goes through the feelings of isolation and loneliness. She thinks that she would not be successful in her future. She feels deeply hurt at the passing comments of other people. In the initial phase of the disease, she had experienced hallucinations. She had frequent doubts that people

are planning plots against her. She says, "*One evening, I made everyone shocked by a strange behaviour. I was mentally down throughout the day. I had experienced severe mood swings and was crying many times. On the evening, I ran out of the house with a knife crying aloud and went to the house of my grandmother. People in the neighbourhood saw me crying and running with knife. The father followed me in a rush and prevented me from the suicidal attempt. There was a similar instance at a later time. I climbed on the top of the house with the intention to hurting myself by jumping down"*. Since the parents were observing every movement of '**A'** closely, they could save her life.

'**D'** feels very sad at the plight of her parents. They lost her younger daughter few months back. Usually, she keeps her pain for herself. She says, "*One day, when I experienced severe pain, I cried aloud. Few days back, I had lost my sister also. While I was crying, I noticed my pappa and mummy crying".* This was a sad dight for her. On that day, she took a decision that she would not make her parents sad. Even though she cries, it would be in the nights when the parents are on their bed.

(Table 14: Pattern matching and rival explanations)

Case	**Emotions in Common**	**Uncommon Emotions**	**Rival Explanations**
A	fear of death, hopelessness about the future, habit of crying, anger issues	Suicidal ideations, isolation	Unable to accept the body image, side effects of the medications.
B	Anger,	Bold, Courageous	Long years of living with SLE
C	Mood swings, anger,	Bold, Courageous	Long years of living with SLE
D	Mood swings, not accepting the disease	Suicidal Ideations	She lost her dearest sister, side effects of medication
E	Anger, mood swings		

Subtheme 2: Body image

From the data collected, it could be found that all the respondents experienced difficulties in accepting their changed body images due to SLE. Obesity, hair loss and the rashes on the skin created difficulties. Though uncomfortable with the obesity issues, '**C'** faced no issues in interacting with the people. '**A'** and '**E'** found it difficult to accept their body due to the obesity. They feel that people around them are making fun of her because of this. The comments of cousins, relatives and others make them upset. Likewise, '**D'** is also upset of the bodily changes that take place. Sometimes, the society views the obesity of the children as a result of their laziness. The bodily changes have brought significant changes in their identities. They felt that they had started to look weird to outsiders. From the analysis, it became clear that the attitude of the participants towards the society is very much linked with their own perceptions of body image as the studies point out (Huangfu, 2020).

Case 'D': "*It was very much difficult for me to accept my loss of hair. Each time I cut my hair, I did it with utmost pain".*

Subtheme 3: Coping strategies to manage psychological challenges

In the case of '**A'**, she fails to accept her bodily changes and try to avoid social functions or gatherings. Other than these, '**A'** has no coping strategies to manage psychological challenges. However, '**A'** feels that speaking with her parents provides her lot of relief. When '**B'** gained weight during the treatment, she separated herself from the friends and the society. '**B'** also reports that the constant support from the part of family and cousins were a source of relief for her. '**C'** shared that the approach of the family, friends, teachers and the doctors offered her emotional relief. Since '**C'** has accepted the bodily changes, she had no difficulties in interacting with others. What helps '**D'** to manage the psychological challenges is the friendship and the presence of parents. For, '**E'**, the sources of strength at times of psychological challenges were parents, friends, teachers.

(Table 15: Coping strategies to manage psychological challenges)

Case	Coping Strategies	Effective Strategies

A	Avoiding social gatherings, Interacting with Parents	Interacting with Parents
B	Social distancing, Rapport with the parents and friends	Rapport with the parents and friends
C	Free interaction with parents, sibling, teachers and friends	Free interaction with parents, sibling, teachers and friends
D	the friendship and the presence of parents	the friendship and the presence of parents
E	the friendship and the presence of parents	the friendship and the presence of parents

From the analysis, it becomes clear that the interaction with the parents or friends is an effective strategy to manage the psychological challenges that may arise in the lives of the children with SLE.

Theme Four: Social challenges

Here, the researcher tries to bring out the social challenges faced by the children with SLE. The particular focus in this section is to understand the respondents' capacity of making relationship with others, ability to participate in the social activities, relationship with the society.

Subtheme 1: Relationships with peers and society

From the data collected, it was found that '**A'** and '**B'** had significant difficulties in relating with the peers following the diagnosis of the disease. Both had a good number of friends. There used to be frequent contacts, telephonic conversations, messages between them prior to the disease. But now, both the respondents feel that their peers do not understand them. Due to this, they have not disclosed the details of the disease to any of them. In the case of '**E'**, only the priest of the church and her two friends know that she has the disease. '**A'** usually do not attend any social functions. She finds it difficult to stand in public. She has pessimistic views about the society. On the other hand, the respondents, '**C'** '**D'** and '**E'** have a cordial relationship with the friends. They feel that the support of their friends has made them happy. The attitude of '**C'** and '**E'** towards the society is pessimistic. '**C'** says, "*I am sad at the comments of the*

neighbours. They think that I am lazy. When they see myself and pappa on scooter, they blame my pappa for making me lazy". They build their own assumptions about the obesity and the disease of the children. They are interested in cooking stories about their disease. Both '**C** and '**D'** find no issues in disclosing the details about the disease to the people.

Cross case synthesis

(Table 16: Cross case synthesis)

Case	Perception of Peers	Perception of Society
A	Broken relationship	Pessimistic views about society
B	Broken relationship	Pessimistic views about society
C	Good relationship	Pessimistic views on society
D	Good relationship	Optimistic views on society
E	Good relationship	Pessimistic views on society.

The above cross case synthesis throw light on the fact that the children with SLE generally have a pessimistic attitude towards society. This finding goes in parallel with the studies (Huangfu, 2020).

Subtheme 2: Coping strategies to manage relationship with the society

From the analysis, it becomes clear that the participants use no coping strategies to manage their pessimistic attitude towards society. However, in the following table, let us try to analyse the details by listing down the relevant information obtained from the interviews. Moreover, it was found that the participants except '**D'** are not interested in disclosing the details about the disease to the public. '**D'** receives a good support from the society

(Table 17: Coping strategies to manage relationship with the society)

Case	Coping Strategies	Explanation
A	No Coping Strategies, keeps a distance	Pessimistic Attitude
B	No Coping Strategies, kept a distance when the disease was active	Pessimistic Attitude

C	No Coping Strategies, keeps a distance	Pessimistic Attitude to society
D	Interacts with the society	Positive attitude to the society
E	No coping strategies, keeps a distance	Pessimistic Attitude

Theme Five: Economic challenges

In this part, the researcher is trying to gather details about the direct (economic) and indirect costs of the disease condition. The different themes will cover aspects like treatment costs, medical insurance and sources of finance of the families.

Subtheme 1: Direct costs of SLE and coping strategies

Except in the case of '**A'**, all the other families struggled a lot to meet the treatment expenses. In the case of '**B'**, the average monthly costs for the treatment is Rs 12000. Until now, her mother, who alone is the breadwinner of the family had to spend nearly 8 lakhs for the treatment alone. She managed to get the money by selling a portion of land, selling all the gold, donation from people around and relatives, meager income from the grocery shop and the salary of the mother (She started to get Rs 10000 every month very recently). The family is not able to avail the benefits of insurance policies.

In the case of '**C'**, she needs to spend Rs 35000 every month on treatment alone. Until now, the family spent around 20 lakhs on the treatment of '**C'**. The sources of money were donation of people and relatives in cash and kind, sale of an acre of cardamom plantation, daily wage of the father. Meanwhile, the family had to sell their auto and car for treatment. Though '**C'** has the health card, it is of no use in the private hospitals. Also, few doctors have helped the family to reduce the medicinal costs by linking them directly with the companies. The friends had initiated a crowd funding for '**C'** and later she had participated in a television program, '*udan panam*' to find money for the treatment.

In the case of '**D'**, until now, the family spent nearly 50 lakhs on the treatment expenses of '**D'**. As of now, the family spends Rs 20000 every month. The family has borrowed a huge amount of money from banks and private financiers. The only source of income

is the daily wage of the father, meager income from the grocery shop and the donations. The govt health card is not recognized in private hospitals.

In the case of '**E'**, until now, the family spent around 3 lakhs for the treatment. While she was under the allopathic treatment, she had to spend Rs 20000 every month on treatment alone. Since she has turned into Ayurveda, the economic cost is Rs 4000 every month. The family has borrowed money from banks and private banking institutions to meet the treatment expenses. The small income from agriculture alone is not enough for the family to treat her.

In the case of '**A'**, the family is financially stable. Moreover, just before the onset of the disease, the family has purchased an insurance policy and the treatment expenses are covered. Also, few doctors have helped the family to reduce the medicinal costs by linking them directly with the companies.

(Table 18: Direct costs and coping strategies)

Cases	**Economic Costs/Challenges**	**Sources of Finance/Coping Strategies**
A	Rs 15000/- every month	Business, Health Insurance
B	Rs 12000/- per month Total – Eight Lakhs	selling a portion of land, selling all the gold, donation from people around and relatives, meager income from the grocery shop and the salary of the mother, **no insurance**
C	Rs 35000/- every month Total- Twenty Lakhs	donation of people and relatives in cash and kind, sale of an acre of cardamom plantation, daily wage of the father, crowdfunding, **no health card benefits**
D	Rs 20000/- every month Total-Fifty Lakhs	daily wage of the father, meager income from the grocery shop and the donations, banks and private financiers, **no health card benefits**

E	Rs 4000/- every month Total- Three Lakhs	borrowed money from banks and private banking institutions, income from agriculture, **no insurance**

From the above table, it becomes amply clear that the families of the participants are facing unprecedented struggles to meet the direct costs of SLE. The sources or the coping strategies to manage the challenge are very often insufficient and unsustainable. Only '**A'** avails the benefits of the insurance. While associating the economic status and the occupations of the caregivers, it becomes clear that all the families except '**A'** are belonging to middle or lower middle class families. Since most of them are working in the unorganized sector, they are forced to use the strategies like the sale of the valuable movable or immovable properties, borrowing money from the private financiers, which in long run would hamper the economic well-being of the family. The direct and indirect costs associated with SLE is clearly brought into picture by the reviewed literatures (Carter, 2016).

Subtheme 2: Indirect costs of SLE

Upon analysis, it is found that all the participants had to bear the indirect costs of SLE. The indirect costs include decreased labour activities and the productivity of the caregivers and the absence in schools or colleges. Case '**A'** is reported to have borne the indirect costs in the fact that she has missed many school days (around three months in school). Also, her father's focus on the business was affected since '**A'** had severe mood swings and suicidal ideations. The life of '**A'** could be saved two times only because the parents were closely following each and every footstep of '**A'**. Case '**B'** also missed many college days. She had to stop the preparation for the civil service examinations temporarily. Due to the bleeding in connection with the menstruation, '**C'** had to sit back in the house for several months. She had to stop the tuition classes which was a source of income in the family. Case '**C'** suffered very much in terms of the indirect costs. In fact, she missed many school days. Her mother had to stop her daily wage work in the estates and MGNREGA scheme. Her father was restricted from working in far places as '**C'** may develop extreme pain at any time, especially during the cold seasons and may need to be taken to hospital in the late nights. '**D'** had to stop her education at her plus two grade due to the disease related factors. '**E'** missed many

school days. Along with that, the brother of '**E'** also missed few classes. The studies also point out that the SLE adversely affects the workplace productivity and academic outcomes of the children with SLE (Bakar, 2020).

Theme Six: Social support systems

In this part, the researcher will try to identify the support systems available for each child with SLE and their families. This can include the support provided by parents, family, health caregivers, different institutions like religion and political.

Subtheme 1: The support systems for children with SLE

Case '**A'** feels that her sources of support at the time of diagnosis were family, religion, teachers and friends. For '**B'**, it was the family and the teachers. For '**C'**, the support systems include family, friends, teachers and well-wishers. The health department of the local self government does a remarkable job. In the case of '**D'**, the sources of support include family, friends, teachers, religion, neighbours etc. In the case of few participants, the society failed to support since the disease details were not properly disclosed. However, the support from the panchayath was less. She had to struggle a lot in getting the disability certificate. Since her disability is not permanent, she is required to renew it every year. For '**E'**, those who render support include family, religion, teacher and friends. '**E'** says, "*I feel happy and lucky because I am surrounded with people who love me and take me seriously. When I go to school, my friends are waiting outside the main gate waiting to carry my bag. The school gave me a wheel chair to help me access".* '**A'** and '**B'** had support from the doctors as well. They helped to decrease the direct treatment costs by linking the patients directly with the drug companies. This really helped the families. There are no governmental schemes for the benefit of the people living with SLE. Moreover, the health card of the government is not accepted in the private hospitals. In all the participants, the parents are the primary support systems.

Subtheme 2: Needs of children with SLE

From the data collected, it can be found that the expressed needs of the participants are mainly psychological and educational. Participants '**A'**, '**B'** and '**E'** report that they have not received adequate health education from the hospitals. All the participants are

found to have referred to google to fill the information gap on the disease. Hence, all the participants have educational needs. Case '**A'** has doubts about the future prospects and challenges of the disease. All the participants have doubts about their future. They worry that they would not be successful in the future. '**A'**, '**C'** and '**D'** enquired the researcher whether he knows any other child with SLE. Thus, it could be inferred that they need children who share their own disease condition as their friends. Also, they needed models who had SLE but came out successfully in the future. From the conversations with the participants '**A'**, '**C'** and '**D'**, the researcher could understand that they were in need of counselling services. '**A'** asked: "*Please tell me the truth…Will my disease be cured? Would I be able to live without medicines? Would I be able to reduce my weight? Will I be successful in my future?*"

5.3 Summary of the Chapter

The above chapter deals with the analysis of the data derived through the interview with the five participants. Through the analysis which is done thematically, the research moves into the heart of the study. Under each theme, the experiences of all the participants and analysed and on the basis of which the interpretations are drawn. The chapter also included discussions wherein the findings from the study are triangulated with the existing body of knowledge. For an effective analysis, the research made use of certain tools like pattern matching, pattern matching and rival explanation and cross case analysis. The tabular presentation of the data helps in the analysis of the data.

CHAPTER SIX

FINDINGS, SUGGESTIONS, CONCLUSIONS

Chapter Six: Findings, Suggestions and Conclusions

6.1 Overview of the Chapter

The objective of the chapter is to summarize the major findings pertaining to the research topic. All the findings discussed below are the outcomes of systematic research and analysis of the data collected. They are very much grounded in the empirical evidence obtained through the interview with the participants. The findings lead to suggestions or potential actions which can bring in changes required for the overall welfare of the children with SLE. The reliability of the findings was triangulated with the literature reviews in the preceding chapter. In this chapter, the findings are discussed under themes which would facilitate smooth generation of the suggestions.

6.2 Findings and Discussions

6.2.1 Research question: What are the challenges faced by the children with SLE?

Medical

Delayed diagnosis is one among the responsible factors for the severity of the disease activity and the flares. It is the reason for the low survival rates of SLE in India. The failure from the part of the caregivers to take the symptoms seriously result in delayed diagnosis.

In all the cases, the families had to go through different hospitals to get the right diagnosis. This resulted in the delay in diagnosis. Also, at times, there was wrong diagnosis.

The researcher found that all the participants are undergoing treatment in hospitals managed by the private sector. From the interview, the researcher found that few government hospitals have developed SLE treatment only recently.

All the cases except one are undergoing treatment in allopathic system of medicine. Case '**E'** undergoes treatment in Ayurveda system and she reports better treatment outcomes with less drug complications and direct cost.

The participants have difficulty in accepting the side effects of the medication. The medications, especially the steroid use cause side effects like obesity, mood swings, depressive symptoms, loss of appetite etc. To manage the obesity, '**B'** had made certain lifestyle changes like control on the diet. It was found to be successful in decreasing the body weight. Other coping strategies like stopping medicines did not help.

It was found that the health education was not sufficient for the patients. Thus, they had to refer to Google which often misled them. The research study found that the hospitals do not provide counselling services for the children and their caregivers.

Physical

SLE is manifested in the cases differently. Each case differs in the symptoms. However, there are commonalities. The common symptoms include skin rashes, leg pain, head ache, swelling, hair loss etc. These are the non-specific symptoms which are common to other ailments also.

In certain cases, the participants may develop differing symptoms which may be due to the factors like disease activity, medications, difference in immune response etc.

There are two types of symptoms in the children: presenting and recurring. The latter ones persist in the individuals despite the treatment. There are both common and differing recurring symptoms. Leg pain, joint pain and swelling are commonly seen recurring symptoms.

As the literatures available point out, it was found that few children with SLE experience flares during extreme cold and warm.

All the participants tried to manage pain using sleep as a coping strategy. Massaging the body was also adopted rarely. But none of these coping strategies were effective.

The participants' Activities of Daily Living (ADL) are severely affected by the onset of the disease. While some are partially affected, few could not even do their personal tasks independently. This causes school absenteeism in the children and workplace absenteeism in the caregivers. Overall, the Health-related Quality of Life (HQOL) is affected.

The support provided by the caregivers or the outsiders have helped the children manage the impairments on ADL.

The research analysis restates whatever is discussed in the literature review about fatigue and energy loss. All the participants experience fatigue which affects adversely their capacity to engage in physical activities, pursuing hobbies etc.

The coping strategies used by the participants to manage fatigue were not successful. Sleeping and the use of mobile phones were the reported coping strategies.

Psychological

SLE patients have a poor quality of life. The psychological challenges that all the participants are almost the same. They include fear of death, hopelessness about the future, habit of crying, anger etc. In fact, suicidal ideations and mood swings are yet other challenges that SLE patients develop. The uncommon challenges are hallucinations, feeling of loneliness.

When the participants are diagnosed with SLE and undergo flares, they will usually go through the grief stages according to Kubler Ross, Denial, Anger, Bargaining Depression, and Acceptance (DABDA). The participants living with SLE for long are able to accept the disease condition.

The suicidal ideations, as the literature review also suggests, are associated with poor body image and medications. Likewise, hallucinations are also the side effects of the medication.

It was also found that living with SLE for long made the participants accept the disease conditions and bold in managing the challenges.

Children with SLE are very much concerned about the changes that take place in their body as part of the disease activity and medications. The obesity, hair loss and rashes on the skin are few of them.

As the studies also point out, it was felt that the attitude of the participants towards the society is very much linked with their own perceptions of body image.

The interaction with the parents, family or friends is an effective strategy to manage the psychological challenges that may arise in the lives of the children with SLE.

Social

The attitude of the children with SLE towards society is generally pessimistic. They feel that the society out is blaming them for the obesity and cooking up stories. Hence many of them do not disclose the disease details to the society. At the same time, the children have a good relationship with the friends.

The researcher found that the friendship between the children with SLE facilitated a better health education and functioned as a better supporting system. It was also found that children aspire to form a group specifically meant for the other children with SLE.

It was found that the children do not use any coping strategies to manage the social challenges other than keeping a distance from the society.

Economic

The families that are financially backward would find it hard to meet the expenses of the treatment. From the data analysed, it was found that the caregivers working in the unorganized sector have difficulty in meeting the treatment expenses.

The direct costs of SLE are quite high. Patients belonging to lower socioeconomic status find it hard to meet the treatment costs. The cost in the private hospitals for the treatment is expensive. Also. Many families do not avail the benefits of the insurance policies. The coping strategies used by the family to manage the financial struggles are often insufficient and unsustainable.

The indirect costs associated with SLE also is high. School absenteeism, loss of work life productivity of the caregivers is the usually encountered indirect costs. The studies also point out that the SLE adversely affects the workplace productivity and academic outcomes of the children with SLE (Bakar, 2020).

Living with SLE for long has adverse outcomes. It gets reflected in the academic outcomes and disease activity.

Social Support

It was found that the support system of all the participants comprised of family, friends and teachers. In all the cases, the school management and the teachers have played a constructive role.

6.2.2 Research question: What are the coping strategies of the children with SLE?

(Table 19: Coping Strategies in General)

Themes	Sub-Themes	Coping Strategies
Road to Diagnosis	Side effects of medicine	Exercises (**A**), Stopped Medicine (**B**,**C**), Shifted to Ayurveda (**E**), Diet (**B**)
	Health education	Google (**A,B,C,E**), Health Care Professionals (**C,D**)
Physical	Pain	Sleeping, Massaging
	Activities of Daily Living	Physical exercises, presence of parents, friends and family, purchase of furniture, wheel chair and vehicle
	Fatigue	Exercise, cycling, social media, sleeping
Psychological	Emotions, Body Image	Interaction with parents, friends and teachers
Economical	Direct Costs	Business, health insurance, sale of land, gold, donation, salary, daily wage, crowd funding, loans from bank and private, agriculture
Social		**NIL**

The above table makes the coping strategies used by the children and the caregivers to manage the challenges clear.

The effective coping strategies, as evolved from the research to manage the complications of medication are shifting to ayurveda and diet.

To manage the impairments on ADL, the effective strategies are found to be the presence of parents and the support of the family, friends and the society.

The interaction with the parents also helps the children to withstand the emotional issues and the wrong perception of the body.

Those participants who availed the benefits of insurance or established direct linkage with the drug companies benefitted economically.

It was also found that no participants could develop an effective strategy to manage their pessimistic attitude towards the society.

6.3 Suggestions

In this section, the researcher lists certain suggestions on the basis of the research findings. The suggestions are arranged in such a way that they flow progressively from the interpretations and findings.

Medical

The study had found that children with SLE, especially those from financially weaker backgrounds approach the government hospitals first. It also found that the hospitals fail in making the right diagnosis. Therefore, government hospitals need to be equipped with rheumatology clinics (pediatric rheumatology), specialists and other laboratory facilities that will help the diagnosis of SLE and its treatment. They need to act as the primary sources of diagnosis and treatment.

The study made it evident that the health education from the part of the healthcare professionals is weak. Therefore, the health providers need to take an active role in the holistic management of SLE. They are to empower the patients with knowledge about their condition and the ability to self-manage. The hospitals can also promote disease awareness among the public to minimize stigma, early recognition of symptoms in both

family and clinical settings The meaningful observance of the world lupus day (10 May) can be used as a platform for this.

More researches is to be encouraged by the Ministry of Health and Family Welfare to identify the impact of cSLE on the affected individuals and society and explore solutions that improve long-term outcomes in the population.

It was noted by the study that the Ayurveda offered treatment which is rather less expensive and with lesser complications. Therefore, the integration of alternative medicine systems, such as Ayurveda, into mainstream treatment approaches is to be encouraged. Consider providing access to a range of treatment options, including both allopathic and alternative medicine, to meet individual patient needs.

From the study, it was evident that the children had difficulties in accepting the side effects of the medications. So, developed strategies to help patients better cope with medication side effects are needed. This may involve providing comprehensive information about potential side effects, offering counselling services, and exploring alternative medications with fewer adverse effects.

Physical

The study found that the healthier lifestyle has better health outcomes. Therefore, a special focus has to be laid on promoting a healthy lifestyle and eating habits for the children with SLE. The literatures state that a healthy eating habit can help manage the lupus nephritis, obesity, manage fatigue and prevent lifestyle diseases.

The study and the literatures unanimously agree that fatigue causes much trouble for the children diagnosed with SLE. The hospitals and the caregivers are to encourage effective coping strategies to manage fatigue. It has to be integrated in the health care management plan. Available literature points out that psychoeducation, counselling, improving social relationships, social support are few among the effective strategies. Aerobic exercises are also identified as effective coping strategies.

The healthcare team that consists of doctors, nurses, therapists and psychologists have to develop a Pain Management Program (PMP) which is a rehabilitative treatment approach for patients suffering with chronic pain. The components of the program are patient education, teaching coping strategies, skills training, goal setting etc.

The study found that the coping strategies used by the children to manage the pain fail quite often. Therefore, effective coping strategies for pain management are to be encouraged beyond sleep and encourage the exploration of other options, such as physical therapy and relaxation techniques. Provide comprehensive support for Activities of Daily Living (ADL) to minimize their impact on school attendance and workplace productivity.

Psychological

Almost all the cases agreed that they did not receive any counselling services from the hospital settings. Hence, specialized psychological support services within hospitals and clinics, offering counselling and therapy for patients and caregivers are to be established.

The children with SLE generally develop poor self-image, as the study points out. Therefore, implement interventions to improve body image perceptions and provide resources to help individuals with SLE navigate changes in their bodies. Promote positive self-esteem and resilience through individual and group counselling sessions.

Social

Considering the finding that the families with SLE may need to go through severe financial crisis, policies are required to be made for the benefit of the families with SLE. This can include providing insurance benefits in both private and public hospitals, monetary support to the caregivers as part of *ashwaasakiranam,* issuance of disability certificates as SLE leads to progressive disability and pensions, if need be, subsidizing the medicines etc.

Since it was found that the children with SLE prefer loneliness and have a pessimistic approach towards society, the support group can function as a platform for the children with SLE and their families to effectively manage the various challenges. This would help them get a better health education, motivated and discuss the concerns. Also, the members who have successfully managed the disease condition are sources of support and relief.

Conduct awareness campaigns to address societal misconceptions about SLE, combat stigma, and foster understanding and support. Provide educational materials and

resources for schools, teachers, and peers to create an inclusive and supportive environment for children with SLE.

Economic

It has been found that the families do not get the benefits of the insurance policies nor do they get the assistance of the government mechanisms. Therefore, develop and expand financial assistance programs to support families from lower socioeconomic backgrounds in meeting the high costs associated with SLE treatment. Collaborate with insurance providers and government agencies to maximize the utilization of available benefits and subsidies.

The study underlined the importance of the indirect costs when estimating the costs associated with SLE. Hence, advocate for workplace accommodations for caregivers and academic accommodations for children with SLE to minimize indirect costs associated with absenteeism and loss of productivity. Work with schools to establish supportive environments that address the specific needs of children with SLE and ensure continuity of education.

6.4 Implications for Social Work Practice

The study, "Challenges and Coping Strategies of Children with Systemic Lupus Erythematosus (SLE)" gives a clear picture of the diverse challenges and coping strategies of the children with SLE. The data collection, its analysis and the interpretation have paved the pay to explore into the different social work interventions. The medico social workers can play a crucial role in disseminating health education to the children with SLE and the families. They can promote disease awareness, decrease stigma and help in the early recognition of the disease. Since more researches are needed to be undertaken in the field, the method of social work research can be used to develop the body of knowledge and influence policy making. The social workers can assist in the development of Pain Management Plan (PMP), teach skills, adaptive coping strategies and provide therapies aiming at improving social relationships and psychological functioning.

6.5 Conclusion

Systemic Lupus Erythematosus (SLE), being one of the auto immune disorders can adversely affect the different healthy organs of the human bodies and lead to death. Though its prevalence is largely seen in the women in the reproductive ages, the childhood onset SLE raises significant challenges. The SLE with its impacts took a heavy toll on the lives of the people living with SLE. The impacts of SLE extends over the different facets of human life- physical, psychological, economic and social. While faced with the different challenges associated with SLE, the existing studies and the lived experiences point out that the coping strategies used by those with SLE are very often ineffective. This called for a deep study on the specific challenges and coping strategies of children living with SLE. Moreover, it has been found that researches pertaining to cSLE in India, especially Kerala is very less. This study attempted to fill this gap in the existing body of knowledge and bring to light the significant challenges and the coping strategies of children with SLE in Kerala. The study aimed to offer some useful suggestions based on the analysis of the data that would help the policy makers, healthcare professionals, caregivers and the society as a whole address the complications associated with SLE.

In the preliminary part of the study, the research topic is introduced with some general information on Lupus, SLE, childhood onset Systemic Lupus Erythematosus (cSLE), its prevalence, causes, symptoms, classifications etc. The section also discussed the statement of the problem and the significance of the study. In the following chapters, a thematic review of literature is done in order to identify the research gap in light of placing the study in the context and explore into the methodology followed in the research. The heart of the study presents the cases and analyses and interprets the data to derive sound findings and suggestions.

The study found that SLE causes different physical complications, even hindering the Activities of Daily Living (ADL) and impairing the health-related quality of life. This explorative study revealed that living with SLE is a terrible experience due to the presence of presenting and recurring symptoms. Also, the fatigue associated with SLE causes loss of energy and low level of happiness. The existing body of knowledge and this study throw light on the fact that delayed diagnosis remains a significant challenge despite of all the medical achievements and advancements. The failure to diagnose the

disease condition at its onset and the failure of the caregivers to read the signs of SLE can lead to adverse outcomes in people with SLE. It has also been found that the participants had difficulties in accepting the side effects of the medication. The complications like obesity, hair loss and rashes on skin hamper the self-esteem of the children and affect the psychic and social well-being of the children with SLE. Likewise, the study on the psychological challenges associated with SLE pointed out that the children faced loneliness, fear of death and hopelessness in the future while some reported hallucinations, episodes of seizures and suicidal ideations. As found in the available literatures, the study also discovered that children with SLE generally have a broken relationship with the society at large and have misconceptions about how the society thinks of them. However, the friendship with peers, support of parents as well as teachers help the children with SLE face the challenges. The study also found that the direct and the indirect costs of SLE are unprecedented and hence in need of urgent measures from the part of the policy makers.

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ANNEXURE

Interview Guide

The following questionnaire aims to gather in-depth information and experience about the challenges and coping strategies of the children with SLE.

Demographic Information

Name:

Age:

Address:

Names of the Parents:

Names of Siblings:

Geographical Location:

City:

Town:

Rural:

Climate of your region:

What grade are you currently in your school:

What type of school are you in:

Private:

Govt:

Educational Qualification of Parents:

Father:

Mother:

Occupation of Parents:

Father:

Mother:

When were you diagnosed with SLE?

Age at the time of diagnosis:

Name of the hospital where you are treated:

Type of Hospital:

Private:

Govt:

Hobbies and Interests:

Physical Challenges

Symptoms and Disease Impact

- How would you describe the symptoms that you experience?
- How do these symptoms affect your overall physical well-being, your daily activities, such as attending school, participating in physical activities, or engaging in hobbies?
- Can you provide specific examples of challenges you face due to the physical symptoms of SLE?

Medication and Treatment

- What medications or treatments are you currently receiving for SLE?
- Are there any side effects or complications associated with the medications or treatments you are receiving?
- How do the medications or treatment regimens impact your daily life, such as adherence to medication schedules, dietary restrictions, or physical limitations?
- Do you get any complementary and alternative health services like counselling or special education services?

Fatigue and Energy Levels

- Do you experience significant fatigue as a result of SLE? If yes, please describe the nature and severity of the fatigue.
- How does this fatigue affect your daily activities, such as attending school, participating in physical activities, or spending time with friends?
- How do you cope with or manage fatigue? Are there any strategies or interventions that have been effective?

Pain and Joint Stiffness

- Do you experience pain or joint stiffness associated with SLE? If yes, please describe the nature and severity of the pain/stiffness.
- How does the pain or joint stiffness impact your ability to engage in physical activities, such as sports or play?
- Can you provide examples of how you manage or cope with the pain or joint stiffness?

Physical Limitations and Challenges

- Are there any physical limitations or challenges you face due to SLE? (e.g., mobility issues, muscle weakness)
- How do these physical limitations impact your daily life, including activities at school, home, or in social settings?

<u>Psychological Challenges</u>

Emotional Well-being

- How would you describe your emotions and overall mood?
- Are there any specific emotions or feelings that you experience related to your SLE?
- Can you give examples of situations or events that make you feel a certain way?
- Are there any situations or circumstances that tend to trigger emotional responses or make you feel particularly vulnerable?

- How do you cope with the emotional challenges that arise from having SLE? Are there any specific strategies or activities that you find helpful in dealing with emotional challenges?
- Who do you turn to for emotional support? This could be family members, friends, healthcare professionals, or support groups.

Body Image and Self Esteem

- Do you ever feel concerned about how your body looks or changes because of your SLE? Can you tell me more about it?
- How does your perception of your physical appearance or changes affect your self-esteem?
- Are there any specific things that make you feel better about yourself or boost your self-esteem?

Social Challenges

Peer Relationships

- How do you feel about your friendships and relationships with peers?
- Have you experienced any changes in your friendships or peer relationships since your diagnosis of SLE?
- Can you provide examples of how your SLE has affected your interactions with friends or peers?

Social Activities and Participation

- What social activities or events do you enjoy participating in?
- Have you noticed any limitations or challenges in participating in these activities due to your SLE?
- Can you give examples of specific activities or events that have been affected by your SLE?

Social Stigma and Misunderstanding

- Have you ever encountered social stigma or misunderstanding from others because of your SLE?

- Can you describe any specific instances where you felt stigmatized or misunderstood?
- How do these experiences impact your self-esteem or sense of belonging?
- Do you feel comfortable talking about your SLE with others, such as friends or classmates? Why or why not?
- Have you disclosed your SLE to others? If yes, how did they react? If not, what are the reasons for not disclosing?
- Are there any difficulties or challenges you face in communicating your SLE-related needs to others?

School Life

- How does your SLE impact your experience at school?
- Have you experienced any challenges in keeping up with schoolwork or attending school because of your SLE?
- Can you provide examples of how your SLE has influenced your relationships with teachers or classmates?

Support Systems

- Do you feel adequately supported by your family, friends, or healthcare team in addressing these challenges?
- How would you describe your relationship with your parents or guardians?
- How would you describe the support and care you receive from your family members in managing your SLE?
- Can you describe the communication patterns and dynamics within your family?
- How involved are your family members in your medical appointments or treatment decisions?

Economic Costs

- Have you ever faced financial difficulties related to your SLE treatment or management?

- Are there any challenges in accessing healthcare services due to financial constraints?
- Are you covered by health insurance? If yes, what type of insurance do you have?
- Are there any specific social or support programs that you or your family benefit from?
- Do you receive any financial assistance or support related to your SLE condition?
- How would you describe your family's overall financial situation?

Future Aspirations

- How do you envision your future, considering your SLE and the social challenges you face?
- Are there any concerns or fears you have about your social life and relationships in the future?
- Is there anything you would like to achieve or change to improve your social well-being?