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Adult Acute Care: Systemic Lupus Erythematosus

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What is systemic lupus erythematosus (SLE)?

Lupus is a chronic inflammatory disease of unknown aetiology that occurs in people with an overactive immune system. This condition is also classified as an autoimmune disease, affecting most major organ systems. Individuals with lupus experience fluctuations between periods of remission (waning) and exacerbation (waxing), characterized by symptoms such as fatigue, chronic pain, and disturbances in self-concept (Robin, 2014).

One of the primary targets for antibodies in lupus is the blood vessels. Raynaud's phenomenon occurs in individuals diagnosed with SLE. In these cases, the fingertips change colour, turning white, blue, and red due to spasms of the arteries when exposed to cold. As the antibodies circulate through the body, lupus can affect any organ and cause a wide range of symptoms. This is one reason why diagnosing SLE can be difficult. For example, when the kidneys are affected, the condition is known *as lupus nephritis* (Sloan et al., 2020).

Treatment varies by severity and may include NSAIDS for arthritis, anti-malarials for skin issues and mild lupus signs. Lupus patients are prone to infections and face higher mortality if they have renal problems (Sloan et al., 2020; Sloan et al., 2021). For more information about the medical and epidemiological context, please see the online learning content for Chapter 11.

Initial symptoms

Early signs of lupus include fatigue, weakness, headaches, poor appetite, frequent infections, sunlight sensitivity, butterfly rash on the face, and rashes around the eyes and lips (Sloan et al., 2020; Connolly, McNally, Moran, and Ryan, 2014).

Hochberg (1997) has established an internationally accepted list of eleven symptoms, four of which are indicative of lupus. The list of symptoms is as follows:

- Malar rash – Malar erythema, flat or raised
- Discoid rash – Erythematous raised patches with scaling and follicular plugging
- Photosensitivity – Rash as an unusual reaction to sunlight
- Oral ulcers – Oral/nasopharyngeal ulcers, usually painless, observed by a physician
- Arthritis – Non-erosive arthritis involving two or fewer peripheral joints with tenderness, swelling, or effusion
- Serositis – Pleuritis or pericarditis
- Renal features – Proteinuria or cellular casts
- Neurological features – Seizures or psychosis
- Haematological features – Haemolysis, leukopenia, lymphopenia or low platelets
- Immunological features – DNA, Smith antibody or antiphospholipid antibodies (based on positive cardiolipin, lupus anticoagulant or false positive syphilis serology).
- Antinuclear antibodies – Abnormal positive ANA test in the absence of drugs known to induce it.

Lupus can damage all organs and sensory systems, increasing the risk of stroke and heart attacks. It can cause joint pain and have severe pregnancy complications, such as miscarriage (Hughes, 1996). Because of its varied symptoms, lupus often differs between individuals and may take years to diagnose. Managing lupus can be frustrating since many symptoms resemble other illnesses, and fatigue – the most debilitating factor – is often dismissed or trivialized (Baker and Wiginton, 1997, p 129).

Lupus resembles rheumatoid arthritis as it causes painful, swollen joints and damages the central nervous system in more than half of patients, leading to symptoms ranging from mild depression to stroke. It can also cause hair loss. Recent advances allow patients to live normal lifespans, but lupus remains a multisystem disorder with no cure. This presents a challenge to all nursing specialities to provide comprehensive care (Ana and David, 2020; Lash, 1994).

Several mechanisms likely cause central nervous system issues in lupus patients, including infections, embolism, and hypercoagulable states. They may experience seizures, stroke, or psychosis, with sudden onset indicating seizures or stroke (Futrell and Millikan, 1994). Living with lupus is challenging, and this study explores its physical and social impacts from the perspectives of patients, carers, and professionals. Patients and families adapt by managing caregiving and chronic disease effects (Permutt, 1994, Bengtsson et al., 2002).

Lupus can be classified into three main types: (1) discoid lupus affects only the skin; (2) drug-induced lupus, which shows lupus-like symptoms that disappear when the offending drug is stopped; and (3) systemic lupus, which causes inflammation in various organs. Of these, only systemic lupus can result in life-threatening involvement of the central nervous system or kidneys. Renal involvement is referred to as lupus nephritis. By the 1960s, lupus nephritis and progressive renal disease had become leading factors in lupus patient morbidity, with kidney failure the most common cause of death (Schiffenbauer and Seigel, 2005).

> [R]enal involvement is one of the most serious complications of systemic lupus erythematosus. It has a major impact on morbidity and mortality. The incidence of renal disease in SLE varies with criteria used to define renal involvement and selection of the patients. Using clinical parameters, the incidence varies from 45% to 75% but it is reasonable to assume that on average, two-thirds of patients with well-documented SLE will develop renal symptoms during their disease course.
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> (Lewis et al., 1999, p. 79)

Lupus and its variants encompass a range of clinical issues, each requiring specific therapy and having different outcomes. The condition is characterized by multiple immunologic abnormalities, including disrupted antibody regulation and the presence of various antigen-antibody complexes. Early diagnosis typically involves identifying circulating serum autoantibodies, which are autoantibodies. Treatment often includes corticosteroids and, for some patients, cytotoxic drugs, also called chemotherapy, which are linked to increased survival rates. Before diagnosing lupus, it is crucial to exclude other conditions, such as infections (Stevens, 1993).

Epidemiology

Approximately 50,000 people in the UK are estimated to have lupus (Lupus UK, 2014). Some experts suggest that the incidence rate is rising, but this could be largely due to better diagnosis rather than an actual increase in cases (Manson and Rahman, 2006). Thanks to improved diagnostic methods that enable earlier detection and treatment, lupus no longer carries the high mortality rates seen in previous years.

The main reason why lupus no longer has the high mortality rate of the past is the development of diagnostic technology, which has contributed to improved tests that enable earlier detection and treatment. Those diagnosed undertake health prevention strategies. In the UK, the 5-year survival rate for lupus patients increased from less than 50% in the 1950s to over 90% in the early millennium (Reeves, 2004). In the 1990s, the prevalence rate (i.e., the number of people per 100,000 of the population) for lupus was 28 per 100,000. The incidence rate (i.e., the number of new cases each year per 100,000 of the population) was 4.7 per 100,000 annually. Therefore, about 26,300 people developed the disease in the 1990s (Lupus UK, 2014). The incidence rates for lupus are higher than those for motor neurone disease (2%) and multiple sclerosis (3%).

The worldwide prevalence of SLE is estimated at 43.7 (15.87 to 108.92) per 100,000 people. Poland, the USA, and Barbados have the highest estimates of SLE incidence; The United Arab Emirates, Barbados, and Brazil recorded the highest SLE prevalence (Tian et al., 2023).

Lupus is a complex disease that impacts both the individual and their family. Lupus affects people of all ages but reaches its peak in the mid-twenties. Women are nine times more susceptible than men, and it is nearly three times more common among Black people than among White people in the UK and the USA (Cortes et al., 2008, Khamashta, 2003). A disease once considered very rare is now believed to affect as many as one in 1,000 young White women. West Indian women might be even more vulnerable. Hospital admission rates per 100,000 population demonstrate that lupus is more prevalent in urban areas such as Manchester, London, and the West Midlands (Goldacre et al., 2005).

Onset (typical age, gender, ethnicity): the UK, the USA, Asia, and the Caribbean

In the USA, the typical age of onset for lupus in the population usually falls between 16 and 55 years, although some individuals do develop late-onset SLE in their sixties. Generally, this condition primarily affects the African American, Asian, and Hispanic populations (Jewett-Tennant, 2025).

In the UK, people usually develop the condition between the ages of 15 and 55. Ninety per cent of lupus cases involve women. Once again, it is reported that individuals from African, Caribbean, and Asian backgrounds are more likely to be affected by the condition than their Caucasian counterparts (The Elgin Clinic, 2025).

In Asia, the prevalence of lupus is reported to be between 30 and 70 per 100,000 people, varying across different countries. Countries such as China have a higher prevalence of 70 per 100,000, while others like Saudi Arabia, India, and Japan have lower rates, ranging from 3.2 to 19.3 per 100,000 of the population (Osio-Salido and Manapat-Reyes, 2010). The average age of onset in this population is between 25.7 and 34.5 years (Jakes et al., 2012).

In the Caribbean, the prevalence of lupus is reported to be higher among women in Barbados, with numbers increasing and aligning with the rates reported in American studies (Flower et al., 2012).

Nossent's (1992) study found that the annual incidence rate for people with lupus on the Caribbean island of Curaçao was highest in 1990 among those aged 15–45, particularly for women. It also noted this had increased, and with this rise, the most common complication among most study participants was renal disease.

A study by Maloney et al. (2017) on people who lived in Jamaica found that the average age of onset for the condition was around 33.5.

All this information suggests that systemic lupus erythematosus is a condition that primarily affects individuals in their working and adult years. This period can range from as young as 16 to as old as the sixties or seventies, depending on the country and retirement age. During this stage of life, individuals experience numerous transitions and changes. Although this condition predominantly affects women, with up to 90% of diagnosed cases being women, men can also develop the condition.

Medical treatment and side effects

Lupus currently has no cure; however, medications are available to help control symptoms and lower the risk of complications like organ damage. The specific drugs prescribed depend on the symptoms and affected body parts.

Medications frequently prescribed for people with lupus include (NHS Inform, 2024):

- Hydroxychloroquine, a medication traditionally used to treat malaria, can assist those with partially active lupus by alleviating fatigue and addressing skin and joint mobility problems.
- Corticosteroids, which are fast-acting anti-inflammatory medications including hydrocortisone and prednisone, can be used to reduce inflammation, calm the immune system, and provide pain relief.
- Other anti-inflammatory drugs classified as non-steroidal (NSAIDS), including aspirin, warfarin, and heparin, can help people with joint and muscle pain.
- Immunosuppressants are medications used to suppress or decrease activity of the immune system, including drugs such as methotrexate and azathioprine. Some of these medications can be employed when it is not feasible to reduce steroid doses, and some require regular blood tests while in use.

Occupational Gift

Caribbean gift to the reader: Display of Christ faith

In the 1990s, Mrs F. a lupus sufferer, made several visits to Israel. This was a pilgrimage to the Holy Land of Jerusalem. She visited the Holy Land with a church party from Quex Road Catholic Church in Kilburn, North London. In the build-up to the event she somehow managed to persuade several of her dear friends to join her on this tour. They made a special effort to be part of this event. Together, as 'sisters in arms' they made the trip and enjoyed it immensely. While in Israel, Mrs F. got to know Stan (now deceased) and his wife. They lived on a kibbutz. Stan was a retired US Naval Officer who had made a conscious decision to return to live in retirement in Israel. Mrs. F and Stan struck up a wonderful and special friendship that lasted until he died in 2003. As friends, they had a special bond. Over the years up until his death in 2003 they would write letters to one another. Every year a gift of oranges would arrive from Israel. Mrs F. really appreciated this gesture.

Many of her friends from across the local community would often visit her in difficult circumstances, sometimes linked to pain and reduced stamina, and at other times because they had problems of their own. She had friends of various religious backgrounds – the Dattani family who practised Hinduism, the Morris family who were Seven Day Adventists, Stan and his wife were practising Jews and the Wright family were Pentecostalists. Multifaith background was not a barrier. Even in these circumstance her gift to them would be to provide gentle advice and special prayers of support. All her friends knew about her illness. She would willingly share information about the disease and for this reason the author is inclined to believe that his friends were all part of her very special 'Lupus Support group' although it was never really framed in that way.

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