Systemic lupus erythematous: nurse and patient education


Abstract
Systemic lupus erythematous (lupus) is an autoimmune disease in which the immune system attacks healthy cells, tissue and organs, including the skin, kidney, heart, lungs, brain, joints and blood vessels. Symptoms of lupus vary between patients. The most common symptoms include unexplained fever, skin rash, swollen or painful joints, fatigue and kidney problems. Lupus can be treated effectively, but there is presently no cure for the condition. People with lupus may experience periods of exacerbation of symptoms, which are termed 'flares', as well as periods of remission. Nurses need to have a good understanding of the disease to provide patients with appropriate support and advice about how to maintain wellbeing and lead active lives.

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Autoimmune disorders, chronic illness, systemic lupus erythematous, women's health

Aims and intended learning outcomes
This article aims to increase nurses’ knowledge and awareness of systemic lupus erythematous (lupus). After reading this article and completing the time out activities you should be able to:
- Define lupus.
- Explain how lupus develops and affects individuals.
- Identify diagnostic tools and treatment options for patients with lupus.
- Outline the effect of lupus on patients’ quality of life.

Introduction
Lupus is an autoimmune disorder associated with significant mortality and morbidity (Gordon 2002). It is caused when the body produces too many auto-antibodies which attack healthy cells, tissue and organs (Sohng 2003). Lupus can affect almost any part of the body and presentation ranges from a rash, anaemia, arthritis and thrombocytopenia to psychosis, inflammation of serosal membrane (serositis), nephritis and seizures (Rahman and Isenberg 2008). Common symptoms of lupus include extreme fatigue, kidney problems, painful or swollen joints and skin rashes (Ehrenstein and Isenberg 2004). At present, there is no cure for lupus and treatments vary widely (Wallace and Hahn 2007).

Epidemiology
Lupus is prevalent worldwide but the proportion of patients with lupus varies between different ethnic groups (Pons-Estel et al 2010). Lupus affects approximately 40 out of every 100,000...
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northern Europeans, more than 200 out of every 100,000 black African and black Caribbean people (Johnson et al 1995) and about 100 per 100,000 Asian people from Bangladesh, India and Pakistan (Isenberg and Manzi 2008). Lupus mostly affects women of child-bearing age (15-50 years). The ratio of females to males with lupus is 9:1 (Pons-Estel et al 2010). In one study in Birmingham, the prevalence of lupus in women aged 18-65 years was estimated at between 54 per 100,000 and 200 per 100,000 individuals (Johnson et al 1996). Although uncommon, children under 15 years and adults over 50 years may also develop lupus (Isenberg and Manzi 2008).

Clinical presentation of lupus may vary between ethnic groups (Hochberg 1997). For example, patients of Caucasian origin who have lupus are susceptible to photosensitivity and may develop a skin rash on sunny days. This increased risk of developing a photosensitive rash is linked to the presence of anti-Ro antibodies in patients with cutaneous lupus (involvement of the skin) (Sontheimer et al 1982).

Black African and black Caribbean patients with lupus are more likely to present with kidney involvement (Isenberg and Manzi 2008). The prognosis for patients with and those without systemic involvement (such as renal disease) also varies. For example, patients with lupus who have renal involvement have a poorer prognosis than those without renal involvement (Gordon 2002). However, the survival rate of patients with renal involvement in the UK has improved from a 56% ten-year survival rate (between 1963 and 1975) to an 81% ten-year survival rate (between 1976 and 1986) (Bono et al 1999).

Pathogenesis

The immune system is designed to protect the body. In patients with lupus, the immune system malfunctions and attacks the healthy cells of the body (Rahman and Isenberg 2008). The exact cause of lupus, the resulting autoimmune inflammatory response and the risks of inheriting the disease are not clear (Ehrenstein and Isenberg 2004). Although different members of the same family can have lupus, the risk of a sibling or child of a parent with lupus also inheriting the disease is low (less than 3%) (Isenberg and Manzi 2008).

Some drugs are known to cause a variant of lupus, known as drug-induced lupus, which affects the skin and joints (Rubin 2002). In the United States alone, approximately 15,000 cases of drug-induced lupus are reported each year (Wallace 2008a). More than 80 drugs have been associated with this type of lupus. These include sulphur-containing drugs, tetracycline and non-steroidal anti-inflammatory drugs.

The use of these agents is associated with one in 1,000 cases of drug-induced lupus (Vasoo 2006). Patients with this condition do not generally fulfil the American College of Rheumatology (ACR) criteria for the classification of lupus (Hochberg 1997) (Box 1), and in 99% of cases symptoms disappear within 12 weeks of withdrawing the drug (Wallace 2008a). Six agents, namely tumour necrosis factor alpha inhibitors, methyldopa, D-penicillamine, hydralazine, procainamide and minocycline, account for 90% of drug-induced lupus (Wallace 2008a).

Box 1 American College of Rheumatology criteria for the classification of lupus

- Malar rash – fixed malar (cheek or cheek bone) erythema, flat or raised.
- Discoid rash – erythematous raised patches with keratotic scaling and follicular plugging; atrophic scarring may occur in older lesions.
- Photosensitivity – skin rash as an unusual reaction to sunlight, diagnosed by patient history or observation by a physician.
- Oral ulcers – oral or nasopharyngeal ulcers, observed by a physician.
- Non-erosive arthritis – involving two or more peripheral joints and characterised by tenderness, swelling or effusion.
- Serositis – pleuritis (convincing history of pleuritic pain, rub heard by physician, or evidence of pericardial effusion) or pericarditis (documented by electrocardiogram, rub or evidence of pericardial effusion).
- Renal disorder – persistent proteinuria (>0.5g/24 hours or 3g/L on a urine dipstick) or cellular casts of any type.
- Neurological disorder – seizures or psychosis in the absence of offending drugs or known metabolic derangements (for example uraemia, ketoacidosis or electrolyte imbalance).
- Haemolytic disorder – haemolytic anaemia or leucopenia (<4,000/mm³ on two or more occasions), lymphopaenia (<1,500/mm³ on two or more occasions), or thrombocytopenia (<100,000/mm³ in the absence of offending drugs).
- Immunological disorder – anti-double stranded deoxyribonucleic acid, or anti-Smith or antiphospholipid antibodies (abnormal immunoglobulin-M or immunoglobulin-G anticardiolipin antibody, lupus anticoagulant or false positive syphillis serology (positive for at least six months and confirmed by Treponema pallidum immobilisation or fluorescent treponemal antibody absorption test)).
- Anti-nuclear antibody – abnormal titre of antinuclear antibody in the absence of drugs known to be associated with the ‘drug-induced lupus’ syndrome.

Note: for identifying patients in clinical studies, a person is diagnosed with systemic lupus erythematous if any four or more of the 11 criteria above are present either serially or simultaneously during any interval of observation (Adapted from Tan et al 1982, Hochberg 1997).
Pathophysiology
Lupus is a chronic, relapsing, inflammatory and often febrile disorder that may involve any organ or system of the body, resulting in inflammation, tissue damage and loss of function (Isenberg et al 2004). The ACR has produced a set of 11 classification criteria used in the diagnosis of lupus (Hochberg 1997) (Box 1). Typically, the ACR classification criteria are used for research purposes. Individuals fulfilling any four of the 11 criteria can be included in lupus studies. Individuals fulfilling two or three of the criteria, especially immunological, antinuclear antibody and haematological blood tests, may develop lupus, but do not yet fulfil sufficient criteria to make a formal diagnosis of the disease (Isenberg et al 2004). Similarly, patients with vague symptoms and no positive blood tests are unlikely to have lupus and should be reassured about their diagnosis.

To be diagnosed with lupus, a patient must present with four or more of the ACR classification criteria (Hochberg 1997) (Box 1). Although all clinical features do not have to present simultaneously, the diagnosis is not confirmed until a fourth feature is present either serially or simultaneously during any interval of clinical observation (Isenberg and Manzi 2008). Patients’ symptoms will vary and may be mild or severe (Box 2). These symptoms may also come and go over time and new symptoms may occur several years after initial diagnosis (Ehrenstein and Isenberg 2004). Some individuals may have multiple organ involvement, while others only have one system of the body involved, for example the skin (Ehrenstein and Isenberg 2004).

Approximately seven out of eight patients who display lupus-like symptoms fail to meet the criteria for diagnosis of lupus (Wallace 2008a) and may receive a diagnosis of undifferentiated connective tissue disease. This disease is often diagnosed when patients demonstrate some features of a connective tissue disease such as lupus, but there are insufficient symptoms or features to establish a firm diagnosis. Such features include inflammatory or vasculopathy features (for example, Raynaud’s phenomenon), a positive antinuclear antibody and positive rheumatoid factor or anti-cyclic citrallinated peptide test (antibodies directed against one or more of an individual’s own proteins). In one third of patients with undifferentiated connective tissue disease, the disease will evolve over time into rheumatoid arthritis or lupus. However, in one third of patients with undifferentiated connective tissue disease, symptoms resolve spontaneously and a further one third will maintain their diagnosis of undifferentiated connective tissue disease (Alarcón et al 1991).

Another autoimmune connective tissue disorder associated with lupus is antiphospholipid syndrome. This syndrome is primarily a haematological disease characterised by thromboembolic events. A diagnosis of antiphospholipid syndrome is made when a patient presents with at least one clinical criterion (for example, vascular thrombosis, pregnancy morbidity or miscarriage) and one laboratory criterion (for example, immunoglobulin-M or immunoglobulin-G isotype anticardiolipin antibody, lupus anticoagulant) (Wallace 2008a). Approximately 35% of patients with lupus will test positive for antiphospholipid antibodies, with one third developing thrombotic events and miscarriages. As a direct consequence, 1% of patients with antiphospholipid syndrome will go on to have thromboembolic events despite adequate therapy (Wallace 2008a).

Neonatal lupus occurs when a child is born to a mother with lupus who has positive anti-Ro antibodies. Anti-Ro antibodies are also present in women with Sjögren’s syndrome, an associated autoimmune disease. In neonatal lupus, antibodies from the mother cross the placenta and interfere with the development of the fetus (Izmirly et al 2007). Neonatal lupus is rare and presents in approximately 5% of babies born to anti-Ro positive mothers (Wallace 2008a). At birth, the infant can present with a transient discoid or subacute

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**BOX 2**

**Categories relating to symptoms and treatment of lupus**

Patients with lupus can be classified into three basic categories:

1. **Quiescent**
   - Lead a normal life.
   - May only present with a rash and/or fatigue.
   - Treatment may include hydroxychloroquine, non-steroidal anti-inflammatory drugs and topical applications.

2. **Stable with occasional flare**
   - May present with rash and/or chest pain.
   - Occasionally calls the nurse advice line.
   - Treatment may include intravenous or oral corticosteroids.

3. **Serious**
   - Presents with kidney, haematological and or brain involvement.
   - Treatment may include continuous corticosteroids and immunosuppressive drugs.
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cutaneous (lupus) rash, which disappears after several weeks, often without treatment (Izmirly et al 2007).

A ratio of 1:20 anti Ro-positive mothers has a child with a rash. Around 2% of these babies also present with cardiac complications, for example congenital heart block (Rahman and Isenberg 2008). Congenital heart block causes abnormalities in the baby’s heart beat and affects cardiac function. In a mild form, no treatment is needed but in severe cases, insertion of a pacemaker at delivery and possible replacement in adulthood may be necessary to regulate the heart’s rhythm (Rahman and Isenberg 2008).

Patients with lupus often experience unpredictable episodes of the disease (flares), followed by periods of remission. The causes of a flare are almost as unpredictable as when the flare will occur, although some known triggers include sunlight, stress and pregnancy (Isenberg and Rahman 2004). Signs of a flare may include malaise, profound fatigue, increasing alopecia, pyrexia, arthralgias, haematuria, dyspnoea and unexplained skin rash. Some useful strategies for patients include discussing their disease with a doctor or nurse specialist before having vaccinations (as they may rarely elicit an immune response that would result in a flare of lupus) and recognising the need to avoid exposure to ultraviolet (UV) radiation to prevent the development of a photosensitive rash. A collaborative patient-doctor relationship that enables the patient to recognise the onset of a flare so treatment can be modified in a timely manner could minimise the effects of a flare (Ehrenstein and Isenberg 2004).

Complete time out activity

Approximately 15% of all cases of lupus are confined to skin manifestations; however, establishing the true prevalence of cutaneous lupus is problematic because many of these cases are managed by dermatologists rather than rheumatologists (Gilliam and Sontheimer 1982). Erythematous eruptions include localised vasculitis or inflammation of the small blood vessels and the deposition of antibodies and complement in the skin (Rahman and Isenberg 2008). The most common lupus rash occurs in a ‘butterfly’ distribution on the face, and affects approximately one third of patients with lupus during the course of the disease (Isenberg and Manzi 2008).

Alopecia is associated with skin involvement. This can be a recurrent problem (in response to treatment or disease inactivity), since the hair may grow back only to be lost again (Isenberg and Manzi 2008). Alopecia may range from mild diffuse hair loss to severe hair loss affecting the entire head. In mild diffuse hair loss, a patient notices more hair loss than usual. For example, they may notice more hair on the pillow in the mornings and/or more hair lost in the sink or bath when washing hair. Although severe alopecia affects less than 10% of patients (Isenberg and Manzi 2008), the change in physical appearance can be psychologically distressing for patients, particularly females, and may affect physical and emotional health (Ng and Chan 2007). Treatment may include the use of intramuscular corticosteroid injections and wigs to disguise the problem. The treatment of severe hair loss is often unsatisfactory and the condition is sometimes permanent.

Skin eruptions and alopecia may be disfiguring in patients with lupus. This change in appearance may lead to problems with body image (Meenakshi et al 2011) and sexuality as it may mean having to wear a wig. Although there are various options of style, texture and colour of wigs available, self-consciousness may still be an issue. Poor body image may become a major problem and may be associated with depression (Monaghan et al 2007).

Implications of poor body image can be important. Body image has been linked to self-esteem in girls and women (Striegel-Moore and Franko 2002), and can affect coping when coming to terms with disease, such as breast cancer (Pikler and Winterowd 2003). Some male patients with lupus have also reported social withdrawal and a negative effect on family activities (Ferenkeh-Koroma 2006).

Complete time out activity

Pregnancy and lupus

Lupus mainly affects women of child-bearing age (Lannes et al 2011). Some 67% of pregnancies in women with lupus are successful, compared with 85% in the general population (Bertolaccini et al 2005). Early medical literature suggested therapeutic abortions as a solution to pregnancies in women with lupus (Wallace and Hahn 2007). However, this view has changed over time, particularly as more than half of pregnancies in women with lupus are relatively normal, with one quarter of pregnancies resulting in premature delivery (Isenberg and Manzi 2008).
Complications associated with pregnancies in women who have lupus include increased rates of premature deliveries and pre-eclampsia, and increased risk of blood clots (Isenberg and Manzi 2008). Therefore, routine close monitoring during pregnancy should include blood pressure, urinalysis, and weight and blood glucose monitoring. A consultant-led birth plan should be developed and more frequent scanning and intervention as needed. For most women with lupus who plan pregnancy when their disease is in remission, they can expect a normal pregnancy without any major complications (Wallace 2008a).

However, pregnant women with lupus should undergo close monitoring by an obstetrician experienced in high-risk pregnancies in collaboration with a rheumatologist familiar with the management of lupus. This will enable early recognition of potential complications and appropriate treatment (Wallace 2008a).

Most lupus flares in pregnant women occur during the first trimester (Lannes et al 2011). Careful planning of an anticipated pregnancy is vital as the outcome for mothers with lupus and their children are best when the woman is in remission. However, the debate about whether or not the extent and frequency of flares increases during pregnancy continues. Up to 30% of patients with lupus may experience postpartum flares between 2-8 weeks after delivery (Wallace 2008a). The most challenging pregnancies to manage are those occurring in women with active renal disease. In these patients, it can be difficult to distinguish between increasing renal activity and pre-eclamptic toxemia.

Pregnant women who carry antiphospholipid antibodies have an increased risk of pregnancy-related complications and are more likely to have first trimester miscarriage (Rai et al 1997, D’Cruz et al 2007). The presence of antiphospholipid antibodies in people with the syndrome or those who are carriers may affect trophoblastic invasion, thus impairing implantation and subsequent development of the placenta (Vashisht and Regan 2005). In the first trimester, mothers with the syndrome may also present with placental abruption, pre-term delivery and intravuterine death (Venkat-Raman et al 2001). There is an important distinction between patients with antiphospholipid syndrome (test positive for antiphospholipid and have already experienced clinical problems such as thrombosis or miscarriage) and antiphospholipid-positive patients with lupus who do not have antiphospholipid syndrome.

Patients who do not have antiphospholipid syndrome are at much lower risk of experiencing complications during pregnancy because it is thought that their antiphospholipid antibodies are of a different type and are less likely to cause harm to patients. As pregnancy progresses, women are more prone to developing thrombosis in the utero-placental vasculature (Vashisht and Regan 2005). It is therefore vital that these women receive careful antenatal surveillance (Venkat-Raman et al 2001), and for delivery to be conducted in a maternity unit with facilities for surgical delivery and neonatal intensive care.

Around 15% of women with recurrent first trimester miscarriage and 21% of women with mid trimester miscarriage test positive for antiphospholipid antibodies (Vashisht and Regan 2005). To make a positive diagnosis of antiphospholipid syndrome, antiphospholipid antibodies must be present on two separate occasions at least six weeks apart to exclude any transient false-positive or false-negative results secondary to infection, laboratory error, or sample preparation (Lupus Anticoagulant Working Party on behalf of the BCSH Haemostasis and Thrombosis Task Force 1991, Khamashta and Hughes 1993).

Administering a combination of low-dose aspirin or low molecular-weight heparin can improve pregnancy outcome significantly, and increases the live birth rate sevenfold (Backos et al 1999). However, this should be discontinued at week 28 to allow the patent ductus arteriosus to close (Wallace 2008a). Nevertheless, it is still important to acknowledge that these births are associated with an increased rate of prematurity and possible neonatal complications (Vashisht and Regan 2005).

According to experts in several national and international specialist units, it is considered to be riskier for the patient to enter into pregnancy without the immunosuppressants that control active disease. Therefore it is now common practice to continue drugs such as azathioprine, hydroxychloroquine and prednisolone. However, the decision to treat has to be made on an individual patient basis with transparent discussions on the risk and benefit of continuing or discontinuing medications. There are several medications contraindicated in pregnancy. These include methotrexate, cyclosporin, cyclophosphamide, mycophenolate mofetil, angiotensin-converting enzyme inhibitors, rituximab and warfarin (Wallace 2008a).

Unplanned pregnancies occasionally occur during and/or after treatment with
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contraindicated drugs. For these patients, the possibility of a good fetal and maternal outcome must be considered before making a decision about termination. There is still some degree of uncertainty associated with pregnancy prognosis and fetal outcome following administration of drugs with teratogenic effects such as cyclophosphomide (Lannes et al 2011). As such, it is important for the nurse or doctor to reiterate the need for adequate contraception and engage in improved patient education on pregnancy risks during immunosuppressive treatment (Lannes et al 2011). Complete time out activity

Diagnostic tools and clinical features

Several blood tests are done at the time of diagnosis to determine the full extent of organ involvement and whether or not a patient fulfils the diagnostic criteria for lupus. These include a full blood count to determine haematological involvement, complement C3 and complement C4, antinuclear antibody, anti-double stranded-deoxyribonucleic acid (DNA) and anti-Smith antibodies. Anti-double stranded-DNA is a specific blood test; 40-70% of patients with lupus have a positive anti-double stranded-DNA, compared to less than 0.5% of the healthy non-lupus population (Rahman and Isenberg 2008). Similarly, approximately 90% of patients with lupus test positive for serum antinuclear antibody (Wallace and Hahn 2007). Antinuclear antibody is not specific and is found in several different diseases and a small percentage of the normal healthy population (Oksenberg and Brassat 2006).

Raised anti-double stranded DNA and simultaneous falling levels of C3 and C4 may be an indication of an impending flare (Isenberg and Manzi 2008). Renal function tests and protein urinalysis are done to exclude kidney involvement. Other specific auto-antibodies include antibodies to Smith (anti-smith) which is present in 10% of Caucasians and in 30% of black African and black Caribbean patients with lupus. Anti Ro (SSA) is detectable in 30-40% and anti-La (SSB) in 10-15% of patients with lupus (Isenberg and Manzi 2008). Anti-Ro is often present in patients with a photosensitive skin rash.

Acute phase reactants, namely erythrocyte sedimentation rate (ESR), plasma viscosity and C-reactive protein (CRP) are also often tested. These are not specific to lupus, but unlike rheumatoid arthritis – where both are elevated in the presence of inflammation – CRP in patients with lupus usually remains within normal limits even when ESR is high. If CRP is elevated in patients with lupus, it is important to consider infection as a potential cause. Other investigations may include a comprehensive metabolic profile, muscle enzymes (for example, creatinine phosphokinase), urinalysis, chest X-ray and electrocardiogram (Wallace 2008a). Complete time out activity

One of the early clinical features of lupus is a butterfly rash. This usually covers a good proportion of both cheeks joined with a narrow area crossing over the bridge of the nose and resembling the shape of a butterfly (Isenberg and Manzi 2008). This area of the face receives greater exposure to sunlight (UVA and UVB) because of its angle and the rash can be worse on the side of the face with exposure to reflected light, for example from the window of a car when driving. The butterfly rash affects approximately 40% of patients who have lupus with the skin often presenting as red and raised, and occasionally blistering (Patel and Werth 2002). The butterfly rash is often accompanied by a discoid (disc-like) rash, both of which are exacerbated by photosensitivity or exposure to sunlight (D’Cruz et al 2007).

Approximately 70% of patients with lupus report photosensitivity to UV rays (Patel and Werth 2002), and 35% of these patients will have a reproducible rash when exposed to UV rays in a controlled setting (Wallace 2008a). UV rays are present on cloudy and sunny days and are at their peak in higher altitudes and at noon (Wallace 2008a). The reaction to UV light can rarely include pyrexia, mild or severe rash, general malaise, adenopathy and arthritis. Although not all patients experience photosensitivity, patients with photosensitivity are affected by the intensity and duration of exposure.

Other features of lupus include Raynaud’s phenomenon (fingers and/or toes turn white, blue and red in response to cold and stress), swelling in the legs or around the eyes, unusual hair loss, mouth ulcers, anaemia, swollen glands, confusion, depression, dizziness, headaches and seizures (Ehrenstein and Isenberg 2004). Similarly, profound tiredness or fatigue, nausea, loss of appetite and weight loss, low platelet count and unexplained fever are also accompanying features of disease onset (D’Cruz et al 2007).
Swelling in the peripheral joints (hands and feet) accompanied by pain on movement is also a frequently reported symptom early in the onset of lupus. If not identified, it may develop into a more severe form of joint inflammation known as arthritis (Koopman and Moreland 2004). In lupus, arthritis tends to be non-erosive unless there is an overlap with other rheumatological diseases such as rheumatoid arthritis. Also, inflammation of the outer layer of the heart (pericarditis) and lungs (pleurisy) resulting in chest pain and dyspnoea is also often seen early in the onset of lupus (Isenberg et al 2004).

Patient education

It is critical to appreciate the psychological effect of lupus and the negative side effects of various medical treatments on patients (Shortall et al 1995). Patients may have issues with concordance, low self-esteem, treatment and capacity for self-care (Moses et al 2005, Ng and Chan 2007). Patient education, advice and support from the nurse specialist and the advice line is paramount as lupus also affects family members (Ferenkeh-Koroma 2006).

Patients with a significant understanding of their disease process and a strong perceived control over their illness are less likely to report feeling depressed or anxious (Pons-Estel et al 2010). Therefore, patient education that combines elements of efficacy enhancement, social support and problem solving is a key aspect of the nurse’s role (Karlson et al 2010). Therefore, patient education that combines elements of efficacy enhancement, social support and problem solving is a key aspect of the nurse’s role (Karlson et al 2010).
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Patient education results in improvement in mental health status and fatigue, despite the persistence of disease activity (Beckerman et al 2011). According to Karlson et al (2004), a targeted intervention (for example, couples-based counselling) that involves a supportive partner or family member is beneficial as it enhances self-efficacy, can improve the couple’s communication, enables problem-focused coping skills and enhances social support. This in turn has the potential to reduce health problems and costs associated with managing a chronic disease such as lupus.

Role of the nurse

Nurses have a key role in supporting patients diagnosed with lupus. The role of the nurse covers a broad spectrum, including nursing instruction, advice and support. Nursing instruction refers to the provision of planned learning methods for patients that enables individuals to expand their health knowledge and influence their self-care behaviour (Pai 2010). There is evidence in the literature acknowledging the positive effects of nursing instruction on patients’ attitudes, knowledge, disease course and care.

Nursing support could range from advice on the use of sun protection when undertaking outdoor activity to scheduling outdoor activity for early morning, late afternoon or early evening to avoid peak sun exposure (Wallace 2008b). Other interventions such as offering advice on a balanced diet, smoking cessation, adequate exercise and rest, and the

References


use of heat or cold therapy (depending on joint symptoms), all help to manage disease activity (Wallace and Hahn 2007). Similarly, pacing (altering periods of rest with activity) can be advised as a means of managing fatigue.

In addition to lifestyle modification advice, other roles the nurse may engage in may include performing urinalysis and close monitoring during pregnancy and screening for diabetes (Gordon 2002).

**Conclusion**

Lupus is a systemic disease that displays a broad spectrum of clinical and immunological manifestations. The disease is caused by a complex set of interaction between genes, hormones and the environment, resulting in major abnormalities of the immune system. The course of lupus is characterised by episodes of flares and remission. Reassuringly, the life expectancy of patients with lupus has improved. However, the illness-induced disruption to lifestyle and daily activity continues to compromise quality of life in some patients. With adequate support and patient education from the nurse, patients can be more actively involved in improving their clinical outcomes and quality of life.

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