

What impact does Antiphospholipid Syndrome have on patients' lives?

In common with many other autoimmune conditions anti phospholipid syndrome is associated with comorbidities and symptoms. These include fatigue tiredness muscle aches and joint pains. Whilst it may be obvious to say that APS will impact on mental health because having a condition has profound impacts on quality of life including taking long-term medication, there is evidence that features such as depression and anxiety may be caused by the immune condition. Mental health changes are much more common in autoimmune conditions than the general population

The Impact of Antiphospholipid Syndrome on Quality of Life, Morbidity, and Mortality

Antiphospholipid syndrome (APS) is an autoimmune disorder characterised by recurrent thrombosis, pregnancy complications, and the presence of antiphospholipid antibodies (aPL). Though its clinical manifestations range from asymptomatic aPL positivity to life-threatening events, the burden of APS on patients' quality of life is substantial and under-recognised.

Morbidity and Functional Impairment

APS can cause deep vein thrombosis, pulmonary embolism, stroke, myocardial infarction, and microvascular complications. These events frequently lead to long-term disability, especially when they occur in young individuals. Patients may experience persistent fatigue, cognitive dysfunction (“brain fog”), headaches, and balance issues, even in the absence of new thrombotic events. Some develop chronic pain syndromes or secondary conditions such as livedo reticularis or valvular heart disease. Those with the severe “catastrophic APS” (CAPS) face multi-organ failure and require intensive care, further compounding the disease’s physical and psychological toll.

Impact on Mental Health and Daily Life

Living with the uncertainty of thrombosis recurrence or pregnancy loss significantly affects mental health. Anxiety and depression are common, particularly in younger patients facing fertility concerns or recurrent miscarriages. The need for lifelong anticoagulation, with its bleeding risks and regular monitoring, adds to treatment burden and lifestyle restrictions, particularly around travel, sports, and diet. Measures of health-related quality of life are worse in APS than the general population and worse still if patients have coexistent immune conditions such as systemic lupus erythematosus (lupus, SLE).

Mortality

Although many patients with APS remain stable with appropriate treatment, mortality is higher than in the general population, particularly in those with arterial events, recurrent thrombosis despite anticoagulation, or CAPS. Causes of death include thrombotic complications, infections, and, in some cases, bleeding due to over-anticoagulation. This is why it is essential that the correct tests are done at the outset of presentation of symptoms.

Conclusion

APS is a chronic condition with serious implications for physical, psychological, and reproductive health. Its unpredictable nature, treatment complexities, and risk of complications contribute to a reduced quality of life and increased morbidity and mortality. Holistic care addressing both medical and psychosocial needs is essential to improving outcomes for patients living with APS.