Autoimmune encephalitis following herpes simplex encephalitis

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What is this condition?

Herpes simplex encephalitis (HSE) is a severe brain infection most commonly caused by herpes simplex virus type 1 (HSV-1). HSV-1 is primarily spread through direct skin-to-skin contact. Although herpes infections commonly cause mild symptoms such as painful cold sores (HSV-1) or genital ulcers (HSV-2), the virus can spread to the brain, leading to rare complications such as encephalitis, which is inflammation of the brain

Sometimes, after the infection has been treated and the virus is no longer active, the body's immune system - which normally fights infection - may mistakenly attack the brain. This is known as Autoimmune Encephalitis (AE).

How common is it?

The exact number of people who develop AE after HSE is uncertain, but research suggests that it is not uncommon. Studies estimate that approximately 7-25% of HSE cases have developed AE weeks to months after the initial infection.

What causes it?

When the virus attacks the brain during HSE infection, small amounts of normal brain proteins can leak out. These proteins are usually hidden from the immune system. In some people, the immune system becomes confused and wrongly recognises these proteins as harmful, producing antibodies that attack them and cause ongoing brain inflammation. It is important to note that this is not a viral reinfection, but rather a reaction of the body's own immune system.

Symptoms

Symptoms can vary from person to person and may range from mild to severe. The onset of symptoms often occurs 1–2 months following HSE. They may present as new problems or as a worsening of pre-existing residual symptoms.

Symptoms can differ depending on age. Children aged 4 years or younger are more prone to developing movement disorders, such as involuntary jerking, abnormal postures, and stiffness, known as choreoathetosis. They are also more likely to experience impaired consciousness or seizures. In children older than 4 years and in adults, cognitive symptoms and psychiatric changes are more common, including confusion, altered behaviour, agitation, anxiety, and delusions. Other symptoms may include intense headaches, memory disturbances, speech and language problems.

Diagnosis

It can be difficult to diagnose AE after HSE, as some symptoms may overlap with those of the original infection. Diagnosis is based on a combination of clinical symptoms, test results, and other investigations.

Blood tests may be carried out to detect antibodies (such as anti-NMDAR antibodies) produced against normal brain proteins. A lumbar puncture is also often performed to obtain a sample of cerebrospinal fluid—the fluid surrounding the brain and spinal cord—to test for these antibodies.

Other diagnostic tools, such as an MRI scan of the brain, may be used to assess for inflammation and other structural changes. An electroencephalogram (EEG) may also be performed to record the brain's electrical activity and identify abnormal patterns or seizures.

The patient's medical history and timing of symptoms are also reviewed by the doctor to formulate an overall diagnosis.

Treatment

Treatment is centred on calming the overactive immune system and reducing brain inflammation. First-line treatment is steroids, which are used to reduce inflammation. Other treatments, such as intravenous immunoglobulin (IVIG), which consists of antibodies taken from healthy donors, or plasma exchange—a procedure that removes harmful antibodies from the blood—may also be used alongside steroids. If symptoms persist or worsen, further immunosuppressive drugs such as rituximab or cyclophosphamide may be used.

Other supportive care may be provided if necessary. This may include anti-epileptic medications if seizures occur. Psychological support may also be needed to address behavioural or emotional changes. Physiotherapy, occupational therapy, and speech and language therapy can also be offered.

Outcomes

Outcomes may vary according to age. Older children and adults tend to respond better to immunotherapy than younger children and may achieve full recovery. Elderly individuals (over 65 years) may have poorer outcomes, partly due to generally reduced cognitive reserve.

Early diagnosis and prompt treatment are important to improve outcomes. After recovery from HSE, regular follow-up with a neurologist is recommended.

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