
Room for improvement in the follow-up for unilateral headache with autonomic symptoms

FROM THE SPECIALTIES

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Quicker diagnosis and a higher standard of follow-up for trigeminal autonomic cephalalgia is possible – and necessary.

The Norwegian Quality Register for Severe Primary Headaches, established in 2022, is a consent-based national quality register of patients with cluster headache, paroxysmal hemicrania, hemicrania continua, short-lasting unilateral neuralgiform headache attacks with conjunctival injection and tearing (SUNCT) and short-lasting unilateral neuralgiform headache attacks with cranial autonomic symptoms (SUNA). Documentation on different treatment options is limited for several of these conditions, although selected patient groups can be offered new forms of treatment. Further research based on data from the Norwegian Headache Register is therefore crucial [\(1\)](#).

Duration of pain differs across trigeminal autonomic cephalalgias and responses to medication vary. Indomethacin is indicated for paroxysmal hemicrania and hemicrania continua [\(2, 3\)](#). Lamotrigine is the first-line treatment for SUNCT/SUNA [\(2\)](#), while the best documented treatment options for cluster headache attacks are triptans, oxygen inhalation, verapamil and nerve stimulation in chronic cases [\(3\)](#).

Headache diary and other aids

For the 253 patients included in the quality register to date, the data show that it took more than six years on average to arrive at the correct diagnosis after the onset of symptoms. The number of patients who were diagnosed within one year of symptom onset varies between hospitals [\(1\)](#). The use of headache diaries prior to consultations also varies, despite evidence indicating their importance in assessing treatment responses [\(1\)](#). Written patient information can also yield

better results from consultations, and here too, we see room for improvement in many hospitals (1). The same applies to patient-reported satisfaction with the treatment provided (1).

How common is trigeminal autonomic cephalalgia?

Data from the Norwegian Patient Registry and the Norwegian Prescribed Drug Registry, linked with reimbursement codes, provide insight into the annual need for specialist health services among these patients. In 2022, the annual incidence per 100,000 inhabitants was 14.5 for cluster headache, 2.2 for hemicrania continua, 1.4 for paroxysmal hemicrania and 1.2 for SUNCT/SUNA (4). Data from a previous Norwegian survey estimated that just over 100 new patients will be diagnosed with cluster headache in Norway each year (5).

Aim to improve standards

The aim of the Norwegian Quality Register for Severe Primary Headaches is to shine a spotlight on these types of headaches in order to hasten diagnosis and improve the standard of follow-up throughout Norway. It is also intended to provide a basis for further research on severe headaches.

We encourage colleagues to use headache diaries and written information in consultations, as this has been documented to have a positive effect on patients with severe primary headaches. We would also like to see more patients invited to participate in the quality register. This would provide more precise register data and draw attention to a patient group for whom the correct diagnosis can take years.

The first author is the clinical lead for the Norwegian Quality Register for Severe Primary Headaches, while the other authors, except for the last author, are members of the medical committee.

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