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ORIGINAL ARTICLE

## Patient satisfaction with conventional, complementary, and alternative treatment for cluster headache in a Norwegian cohort

SVEIN I. BEKKELUND<sup>1,2</sup>, HILDE K. OFTE<sup>3</sup> & KARL B. ALSTADHAUG<sup>2,3</sup>

<sup>1</sup>Department of Neurology, University Hospital of North Norway, Tromsø, <sup>2</sup>Institute of Clinical Medicine, University of Tromsø, Norway, and <sup>3</sup>Department of Neurology, Nordland Hospital Trust, Bodø, Norway

### Abstract

**Objective.** Cluster headache (CH) may cause excruciating pain and not all patients get satisfactory help. Patient dissatisfaction with general practitioners (GPs) and neurologists, and use of complementary and alternative treatment (CAM) may reflect this. The authors studied patient satisfaction with doctors' treatment and use of CAM in a Norwegian CH cohort. **Subjects.** A total of 196 subjects with a cluster headache diagnosis were identified in the registers of two neurological departments in North Norway. **Design.** Of these, 70 with a confirmed diagnosis according to the second edition of the International Classification of Headache Disorders (ICHD-2) completed a comprehensive questionnaire with questions concerning satisfaction with doctors' treatment, use of CAM, and effect of both treatment regimes. **Results.** Satisfaction with doctors' treatment was reported in 44/70 (63%) (GPs) and 50/70 (71%) (neurologists) while 39/70 (56%) were satisfied with both. Too long a time to diagnosis, median four years, was the most commonly reported claim regarding doctors' treatment. Use of CAM was reported in 27/70 (39%), and 14/70 (20%) reported experience with  $\geq 2$  CAM. Ten patients reported benefit from CAM (37% of "CAM users"). The average cluster period was longer in CAM-users than others ( $p = 0.02$ ), but CAM use was not associated with age, education, use of medication, effect of conventional treatment, duration of cluster attacks, or time to diagnosis. **Conclusion.** About two-thirds of CH patients were satisfied with treatment from either GPs or neurologists, and about one-third had used CAM. Despite experiencing diagnostic delay and severe pain, cluster patients seem in general to be satisfied with doctors' conventional treatment.

**Key Words:** Cluster headache, complementary and alternative medicine, effect, general practice, Norway, patient satisfaction, survey, treatment effect

### Introduction

Cluster headache (CH) is infrequent, but important because it represents an exceedingly painful disorder that disables the patients and disrupts daily activities. CH increases the likelihood of absenteeism and represents increased direct and indirect costs to the society [1,2]. The prevalence of CH worldwide is incompletely investigated, but is reported to be 0.3% in a Norwegian population [3]. CH is about three times more common in men than women, and occurs typically in bouts lasting for weeks with series of stereotypical headache attacks accompanied by ipsilateral autonomic symptoms [4,5]. Like other

primary headaches, especially migraine, CH may go diagnostically unrecognized or may be misclassified by doctors for several years [6,7]. According to a previous study in our area, patients with headache are more satisfied when they receive a correct diagnosis, even when treatment is not prescribed [8]. Despite limited knowledge about the pathophysiology of CH, both acute and preventive treatment options are available and are effective in many patients. In the acute phase, about 75% of patients achieve pain relief on triptans, while oxygen is effective in more than half of patients [9,10]. Data on prophylactic drugs are more limited, but verapamil

Correspondence: Karl. B. Alstadhaug, Department of Neurology, Nordland Hospital, Prinsensgt. 164, 8092 Bodø, Norway. Tel: +47 75534000. E-mail: Karl.bjornar.alstadhaug@nlsh.no

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Cluster headache is an excruciating painful condition that may be challenging to diagnose and treat.

- This study confirms previous European studies showing that around one-third of cluster patients have experience of CAM.
- The use of CAM was associated with longer average cluster periods, but no other factor indicating unsatisfactory treatment.
- Cluster patients are satisfied with doctors' conventional treatment, but diagnostic delay is frequently reported as a reason for dissatisfaction.

and corticosteroids are commonly used. Lithium, methysergide, and melatonin may be tried [11,12].

For several reasons, patients with CH may experience limited or undesirable effects of traditional treatment and may therefore search for alternatives. In two European studies, about 30% of CH patients had used complementary or alternative medicine (CAM) [6,13]. Some 12% had experience of more than one therapy, while 7% had used three or more [13]. Little is known about CH patients' experiences with treatment and why some are less satisfied. We aimed to study patient satisfaction with doctor's treatment and frequency and perceived efficacy of CAM in CH patients living in North Norway.

## Material and methods

### *Design and participants*

Patients with CH were recruited via the two northernmost Norwegian hospitals (Bodø and Tromsø) providing a generalized neurological service to about 460 000 inhabitants living scattered in a geographical area of more than one-third of the country. A list of patients registered with the diagnose G 44.0 between 1 January 2000 and 31 December 2010 according to the ICD-10 [14] criteria were validated and patients who did not fulfil the criteria for episodic CH in the second edition of the International Classification of Headache Disorders (ICHD-2) [5] were contacted by telephone for final diagnostic evaluation. Also non-responders were contacted by telephone to be motivated. The following inclusion criteria were used: (i) age  $\geq 18$  years at study time and (ii) episodic CH according to the ICDH-2 criteria [5]. Exclusion criteria were: (i) inadequate Norwegian language skills, i.e. not being able to complete the questionnaire, (ii) secondary headache, (iii) chronic CH. Further details have been published previously [15].

All data were obtained using a questionnaire covering personal and demographic data, clinical data including pharmacological treatment, use of CAM, and patient satisfaction with headache treatment by GPs and neurologists. The following descriptive parameters were registered: "age", "age at onset of CH", "education level", "work compensation", "smoking and alcohol consumption", "average duration of CH bouts", "effect of drugs on a scale from 0–10" (0 = no effect, 10 = complete pain relief), "use of triptans and oxygen", "use of prophylactic medication", "concomitant diseases", "satisfaction with headache treatment given by GPs and neurologists". CAM was defined as either use of "acupuncture", "homeopathic substances", "chiropractic treatment", and "manual therapy", which are commonly used in our area, and additional space was provided to describe further alternatives. Information on CAM included "Have you ever tried alternative treatment for CH?" and "How did CAM work?", giving the alternatives: "no change", "prolonged cluster bouts", "less intense pain", "more intensive pain", and "shorter cluster bouts". The following assessments were chosen as options for not being satisfied with GPs and neurologists: "it took too long a time to diagnosis", "received treatment for the wrong diseases", "the drug was correct, but didn't work", "it took too long a time to get a consultation with the doctor", and "the doctor had too little knowledge about the disease". It was possible to give more than one answer to the questions.

### *Statistical analysis and approval*

Data were analysed with SPSS software (version 12.0 for Windows). Descriptive data are presented as mean or median, frequency, and standard deviation (SD). Most of the data were ordinal and categorical. To compare frequencies, a chi-squared test was performed. We used a nonparametric test (Mann–Whitney U-test) to test whether subgroups of those using CAM ( $n = 27$ ) were associated with disease-related parameters since these variables were skewed. A  $p$ -value less than 0.05 was regarded as significant. The project was approved by the Regional Committees for Medical and Health Research Ethics North. Data registration was approved by the Norwegian Social Science Data Services. All patients gave written consent for participation.

## Results

From a total of 196 subjects with a registered CH diagnosis, 70 with a confirmed diagnosis completed the questionnaire (Figure 1). Demographic and

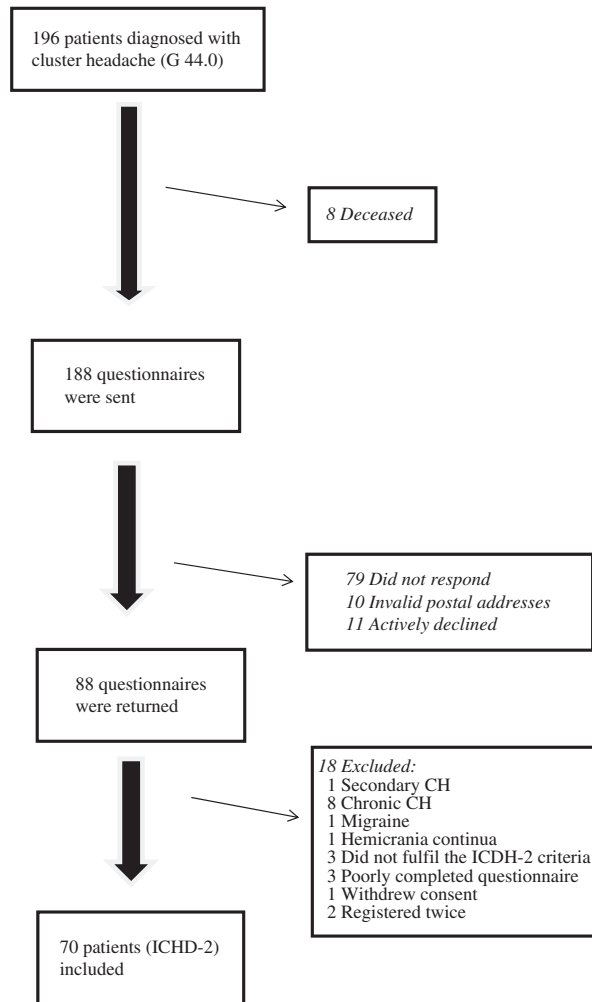


Figure 1. The flow chart shows the recruitment of patients to the study. Of 196 subjects registered with a cluster headache diagnosis, 70 completed the questionnaire-based survey.

clinical characteristics are listed in Table I. The gender proportion was 4.8:1 (m:f). Use of triptans as acute treatment was reported by 49/70 (70%), while 21/70 (30%) used oxygen (Table I). Mean score in evaluating treatment effect was 8.0 (SD = 2.2) for acute treatment and 6.1 (SD = 2.5) for preventive therapy (Table I). A minority ( $n = 9$ ) reported  $\leq 5$  scores. Previous disorders, including stroke ( $n = 1$ ), hypertension ( $n = 18$ ), sinus problems ( $n = 9$ ), and migraine ( $n = 12$ ), were approximately equally distributed between the subgroup of CH who reported use of CAM compared with others.

Forty-four (63%) of the patients were satisfied with the headache treatment from their GPs, while 25/70 (36%) were not. One did not answer. Based on the same questions, the patients reported that they were satisfied with the headache treatment from the neurologist in 50/70 (71%) cases. Twenty patients (29%) were not satisfied. Reasons for not being satisfied with doctors are displayed in Table II. Too long

Table I. Social and clinical characteristics in 70 patients with cluster headache.

Variables	Cluster patients
Age, years, mean (SD)	49.3 (13.9)
Work compensation, n (%)	32 (46)
Current smoker, n (%)	31 (44)
Previous smoker, n (%)	27 (38.5)
Alcohol, less than average, n (%)	27 (39)
Alcohol, average, n (%)	32 (45.5)
Alcohol, more than average, n (%)	4 (6)
Don't drink, n (%)	6 (9)
Use of illicit drugs, n (%)	1 (1.5)
Age at disease onset, mean (SD)	32.4 (14)
Use of triptans, n (%)	49 (70)
Use of oxygen, n (%)	21 (30)
Use of prophylactic treatment, n (%)	25 (36)
Previous or present use of CAM, n (%)	27 (39)
Time to diagnose, median year (min-max)	4 (0-30)
Cluster duration, median weeks (min-max)	5 (1-26)
Attack duration, median min (min-max)	55 (10-480)
Acute treatment effect, median (min-max)	8 (2-10)
Preventive effect, median (min-max)	6 (0-10)

Notes: SD = standard deviation. CAM = complementary and alternative treatment. VAS = visual analogue scale from 0-10 (0 = no effect, 10 = complete symptom relief).

a time to diagnosis and treatment for wrong diagnosis were the most commonly reported reasons for dissatisfaction with general practitioners while time to diagnosis and long waiting time to consultation were the main reasons for not being satisfied with the neurologist (Table II). More than half of the patients were satisfied with both GPs and neurologists (Table II). No significant differences were found for any parameter between "CAM users" and others.

Twenty-seven (39%) reported that they currently used or had previously used one or more CAM

Table II. Satisfaction with headache treatment by GPs and neurologists reported by 70 cluster headache patients.

Patient's assessment of doctor's treatment	Cluster headache patients n (%)
Satisfied with GP	44 (63)
Reasons for not being satisfied with GP:	
Too long a time to diagnosis	18 (26)
Treated for wrong disease	8 (11)
The drug was correct, but didn't work	3 (4)
Too long a waiting time to consultation	3 (4)
Too little knowledge about headache	2 (3)
Satisfied with neurologist	50 (71)
Reasons for not being satisfied with neurologist:	
Too long a time to diagnosis	8 (11)
Treated for wrong disease	1 (1)
The drug was correct, but didn't work	1 (1)
Too long waiting time to consultation	8 (11)
Too little knowledge about headache	5 (7)
Satisfied with GP and neurologist	39 (56)
Dissatisfied with GP and neurologist	14 (20)

Note: GP = general practitioner.

treatments. Acupuncture, the most commonly reported CAM, was used in 20/70 (29%), while 13/70 (19%) had tried chiropractic treatment. One patient each reported physiotherapy, illicit drug (cannabis), naprapathic treatment, healing, scuba diving, reflexology, or dental treatment. Fourteen (20%) reported use of  $\geq$  two different CAMs while 7/70 (10%) reported use of three CAMs or more. Ten patients, 37% of "CAM users", reported improvement of headache when using CAM, most frequently acupuncture. One patient reported more intensive headache pain when using a homeopathic substance. The majority of patients who reported benefit from CAM were also satisfied with GPs (9/10) and neurologists (7/10), and among these patients 5/10 used triptans as acute therapy, 2/10 used oxygen, and 4/10 used preventive drugs. In the total subgroup of "CAM users", 9/27 (33%) were dissatisfied with GPs because of diagnostic delay, while 6/27 (22%) were dissatisfied with diagnostic delay in neurological care. Among "non-CAM users", 9/43 (21%) reported diagnostic latency by GPs and 2/43 (5%) by the neurologists. Among eight patients reporting dissatisfaction due to diagnostic delay to specialist, five were "CAM users" and three "non-CAM users". In the subgroup of patients dissatisfied with the neurologists due to long waiting time, two out of eight were "CAM users" and six out of eight were "non CAM users". The median duration of one cluster bout was seven weeks in those using CAM compared with four weeks in "non-CAM users" ( $p=0.02$ ). There were no statistical associations among use of CAM and age, age at disease onset, use of medication, effect of acute and preventive treatment, duration of cluster attacks, or time to diagnosis.

## Discussion

The present study documents that the majority of the patients were satisfied with the treatment from GPs (63%) and neurologists (71%). Almost 40% in this Norwegian CH cohort have experience of CAM. Treatment satisfaction with doctors was not significantly different between CAM users and others.

The diagnosis of CH is purely based on clinical investigation. Diagnostic delay is an obvious cause of patient distress and could be avoided with increased education and focus on the disorder [16]. Typical symptoms of severe short-lasting strict unilateral pain attacks around the eye accompanied by ipsilateral autonomic features should not be misleading. Also, recurrent bouts are highly characteristic and point to the diagnosis [17]. Despite a shorter diagnostic delay (median four years) compared with previous reports (about seven years)

[6,7,16], diagnostic delay was the most common reported problem in our patients' experience of doctors' treatment. Neither the present study nor others have investigated in depth whether this is due to patient's or doctor's delay or both. In the present study, one important reason for being less satisfied with GPs was treatment for the wrong disease, while long waiting time to consultation was a reason for not being satisfied with the neurologists. The reasons for being satisfied with the doctors were not evaluated in this survey, which could have added important knowledge on the doctor-patient relationship. Studies on treatment effect, trigger factors, and other variables influencing the treatment process should include patient perspectives in order to cover a broader spectrum of the disease management. According to a Danish study, one-quarter of the CH patients had impaired ability to perform daily activities such as housework and social activities while absence from work was almost three times more common in CH patients than others [1].

In a Norwegian population survey from 2012, 45% of the participants reported use of CAM within the last 12 months, most commonly massage (23%) and acupuncture (10%) [18]. In total, we found a lower frequency of CAM, but still three times more of the CH sufferers had used acupuncture compared with the general Norwegian population. The corresponding figures from a national survey in the USA from 2011 were 50% among those with migraine or severe headache compared with 34% in the general population without headache [19]. Such results depend largely on how CAM is defined, whether CAM use is recorded before or after diagnostic confirmation, and a number of other methodological, clinical, and demographic variables that need to be accounted for. Use of CAM has not been investigated among CH patients living in Norway, but CAM use is nevertheless common in headache. In a recent population study in Norway, 62% of those with primary chronic headache and 72% with secondary chronic headache had used CAM, most frequently acupuncture and chiropractic treatment [20]. A high use of CAM in primary headache disorders is confirmed by others [21] but, according to a review of the literature, the methodology used in many CAM studies is not optimal and the prevalence of CAM use varies largely [22,23].

Based on a structured interview, Rossi et al. found that 8% reported a positive effect of CAM [13]. Acupuncture was the most commonly reported treatment (30%), followed by homeopathy (14%) [13]. We found a higher frequency of experience with multiple CAMs (20%) compared with the Italian study (12%), but confirmed the finding that acupuncture was the most commonly



used treatment [13]. Use of CAM in the Italian study was associated with increased age, longer disease duration, chronification, moderate intensity, and they were more satisfied with prophylactic treatment. We found no association between CAM use and age, education, or use of medication. Although 10 patients reported a positive effect of CAM, there is no further information about the significance of this effect. A short time of well-being after treatment, placebo effects, and regression to the mean are alternative explanations that are not possible to adjust for in this study. Subgroup analyses should be interpreted carefully due to small numbers, but we found a tendency for "CAM users" to report dissatisfaction due to diagnostic delay more frequently.

Despite the efforts to include as many CH patients as possible, the small number is a significant concern for the inference of the study, and it does not reflect the actual prevalence of CH [3]. Selection bias should be suspected, and the findings may be representative only for those who actually seek medical attention. On the other hand, cluster attacks are excruciatingly painful and there is reason to believe that the majority of CH patients at some point will be referred to a neurological department, at least in our region where there is no private neurology service. We do not have any knowledge concerning patients in the region who are only diagnosed and treated by GPs. Nor do we have any estimate of undiagnosed individuals in our region. Recent data suggest that women with CH have different disease characteristics from men, such as earlier disease onset, higher frequency of family history, migraine is more often a trigger for CH attacks, and they are less responsive to preventive treatment [24]. A higher frequency of smokers has been reported in CH, and overuse of alcohol has been questioned, although not proven. The question of a possible association between CH and certain personality traits has been raised [25]. No indication of higher frequency of current smokers or excessive alcohol in CAM users was detected in this population, although when including previous smokers, 83% of the cohort reported a history of smoking, which is more than expected.

The assumption that tertiary headache centres should be offered to the population cannot be drawn, but the fact that more than one-third were not satisfied with the GPs and almost 30% not satisfied with the neurologist, while 20% were not satisfied with any doctor, suggests that the headache service in our area is suboptimal and should be improved. More knowledge about factors associated with difficulties in treating CH patients or subgroups with difficult disease should be identified.

## Conclusion

Our survey of patient satisfaction with conventional and complementary and alternative treatment for cluster headache showed that a majority of the patients were satisfied with conventional treatment, while 14% were satisfied with CAM. Some 20% of the patients were not satisfied with any doctor. Reasons for being dissatisfied with primary physicians were too long a time to diagnosis and treatment for wrong diagnoses, while too long a time to diagnosis and too long a waiting time to consultation were the most commonly reported problems related to neurological care.

## Declaration of interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of the paper.

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