# Epidemiologic study of cluster headache prevalence in a medium-size city in Brazil

Estudo epidemiológico da prevalência da cefaleia em salvas em uma cidade de médio porte do Brasil

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#### **ABSTRACT**

To determine the prevalence of cluster headache (CH) in Barbacena, a medium-size city in the State of Minas Gerais, Brazil. **Methods:** The total population of Barbacena is 126,284 inhabitants and the Family Health Strategy Program covers 84,610 of them. In order to identify patients with cluster headache, 36,145 of these inhabitants were screened, following which, a questionnaire was completed by 181 health agents distributed throughout the 28 health posts belonging to the Family Health Strategy network. The completed questionnaires were selected based on the clinical criteria established by the International Headache Society, and those patients (18 years of age or older) with a possible CH diagnosis were later assessed by a headache specialist. This was an observational, cross-sectional study. **Results:** In all, 15 patients were diagnosed as having CH, comprising a prevalence of 0.0414%; or 41.4/100,000 inhabitants. **Conclusion:** The prevalence of cluster headache in Barbacena was lower than that observed in many locations worldwide.

Keywords: prevalence; epidemiology; cluster headache; family health strategy.

#### **RESUMO**

Determinar a prevalência de cefaléia em Salvas (CS) em Barbacena, uma cidade de tamanho médio do Estado de Minas Gerais, Brasil. **Métodos:** A população total de Barbacena, totaliza 126.284 habitantes e o Programa de Estratégia de Saúde da Família cobre 84.610 deles. A fim de identificar pacientes com Cefaléia em Salvas, 36.145 deles foram rastreados através de um questionário que foi completado por 181 agentes de saúde, distribuídos entre os 28 postos de saúde pertencentes à rede de Estratégia de Saúde da Família. Os questionários preenchidos foram selecionados com base nos critérios clínicos estabelecidos pela International Headache Society, e aqueles pacientes (com idade igual ou maior de 18 anos) com um possível diagnóstico de CH foram posteriormente avaliados por um especialista em dor de cabeça. Este é um estudo observacional, transversal. **Resultados:** No total, 15 pacientes foram diagnosticados com CH, compreendendo uma prevalência de 0,0414%; ou 41,4 / 100,000 habitantes. **Conclusão:** A prevalência de Cefaleia em Salvas em Barbacena foi menor do que a observada em muitos locais do mundo.

Palavras-chave: prevalência; epidemiologia; cefaleia histamínica; estratégia saúde da família.

In the group of primary headaches, there is an important category of pain with autonomic trigeminal involvement known as cluster headache (CH), which has the clinical distinction of being one of the most painful headaches<sup>1,2</sup>. Despite presenting with characteristic signs and symptoms, it is necessary to make a differential diagnosis, particularly between migraine, chronic paroxysmal hemicrania and trigeminal neuralgia, to enable the diagnosis and treatment of CH with confidence.

Cluster headache is a clinical entity with diagnostic criteria that are highly specific and sensitive<sup>3</sup>, like those of other primary headaches. Among the clinical particularities of CH, we highlight a unilateral headache of severe intensity, occurring in short attacks (30-180 minutes), and concomitant autonomic symptoms [e.g. tearing (84–91%), eyelid ptosis (57–74%), nasal congestion (48–72%) and/or rhinorrhea (43–72%)], in the patients<sup>4</sup>. Most patients have a circannual and circadian periodicity<sup>2,4,5</sup>. Attacks tend to occur between once every other day and eight times a day, generally lasting from 4–12 weeks, followed by a pain-free period of one to two years, with reports of remission of up to 20 years. According to one prospective clinical study, the mean maximum duration of a crisis was 159 minutes, while the mean duration was 72 minutes among their patients<sup>1</sup>.

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A review by Almeida<sup>1</sup> of the prevalence of CH, refers to studies in the following populations: 0.1% in Denmark; 0.08% in women and 0.4% in men in USA; 0.09% in Sweden and 0.07% in the Republic of San Marino.

According to a meta-analysis carried out by Fischera and coworkers<sup>6</sup> in 2004, the one-year prevalence was 0.54%. However, the authors emphasized the difficulty in establishing the prevalence, due to the differences between studies when it came to methodology, population and diagnostic criteria, which hindered comparisons between the data<sup>6</sup>.

The objective of this study was to determine the prevalence of CH in the population of Barbacena, a medium-size city in the State of Minas Gerais, Brazil, and the effectiveness of the Brazilian health system and its employees in identifying CH patients using a questionnaire.

#### **METHOD**

## Study outline

This was an observational cross-sectional study, which occurred from June 2015 to June 2016, that sought to determine the lifetime prevalence of CH in the population of Barbacena, Brazil. The age, sex, marital status, education, income, and profession of CH patients were also evaluated. All patients meeting the two criteria in the questionnaire—strictly unilateral headache with tearing—were also evaluated by a neurologist specializing in headache.

## **Population**

The population in the city of Barbacena, Brazil is 126,284, and covers an area of 759,186  $\rm km^2$  <sup>7</sup>. The study was carried out in this city for its convenience for most of the researchers who live there, and for having demographic characteristics that are similar to those found in other cities of similar size in Brazil.

The Family Health Strategy (FHS) Program covers 84,610 inhabitants, which is 67% of the population of Barbacena. In this study, 36,145 of the inhabitants were included.

In order to identify patients with CH in the study population, we carried out a screening, followed by the application of a questionnaire by 181 health agents distributed among the 28 health posts belonging to the FHS network.

In Brazil, the FHS acts as part of a governmental strategy to reorganize basic health care. It is based on the precepts of *Sistema Único de Saúde - SUS* (Brazil's public health system), the purpose of which is to improve the effectiveness and impact of basic health care on the health of people and communities. The FHS multidisciplinary team is made up of a number of professionals, including a general practitioner, also called a family health specialist or family and community physician; a general nurse, also called a family health specialist; a nursing assistant, and community health agents who were responsible for the application of the questionnaire.

## Inclusion and exclusion criteria for the study

The following were adopted as inclusion criteria:

- Patients who agreed to participate in the research;
- Patients aged 18 years or older; and
- Patients reporting some type of headache with autonomic symptoms.

The following were adopted as exclusion criteria:

- Patients who were known to have any illness preventing them from understanding the questionnaire;
- Patients who did not report headaches.

## Research tools

For the initial population screening and the control of the number of people approached for the project, a list was built containing the following information: the total number of selected individuals during the initial screening, the number of people with headache, and the number of patients with tearing. This list took tearing into account as it is the most prevalent sign associated with CH<sup>4</sup>.

Individuals who reported headache and tearing answered an informal-language questionnaire containing objective questions (yes or no) that were based on the International Classification of Headache Disorders (ICHD) criteria, to aid the health agents in the identification of possible CH patients<sup>8</sup>. Those patients who did not present with tearing, but presented with other clinical characteristics of CH, were also evaluated by a neurologist.

In order to formulate the aforementioned question naire and establish a diagnosis of CH, we used the criteria defined by the  $\rm ICHD^9$ :

- 1. At least five attacks fulfilling the criteria from B to D.
- 2. Severe or very severe, unilateral, supraorbital and/or temporal pain lasting 15–180 minutes (when untreated).
  - 3. Either or both of the following:
- 3.1. At least one of the following ipsilateral signs or symptoms:
  - a) Conjunctival hyperemia and/or tearing;
  - b) Nasal congestion or rhinorrhea;
  - c) Eyelid edema;
  - d) Forehead and facial sweating;
  - e) Forehead and facial flushing;
  - f) Sensation of fullness in the ear;
  - g) Miosis and/or ptosis.
  - 3.2. Sense of agitation or restlessness.
- 4. The attacks have a frequency of between one every other day and eight per day, for more than half of the time during the active stage.
  - 5. Not better explained by another ICHD-3 beta diagnosis.

# **Project execution**

At first, we established contact with the city's Department of Health by presenting a cover letter for the project and obtaining authorization for the study. After approval, we carried out preliminary research with a randomly-selected unit of the Family Health Strategy program to assess the feasibility of the study.

In the first stage of the project, the health agents received basic information on CH. This training was carried out using multimedia resources, including a presentation in PowerPoint format, and distribution of a book containing the specific characteristics of the headache in question. Following training, the agents were given a list containing the identification of the FHS, name of the agent, area of performance, number of homes visited by the agent, and number of residents, the presence or absence of headache, and presence or absence of tearing.

In the second stage of the project, the questionnaires were evaluated, selected and assessed by the neurologist for the purpose of ruling out possible false-positive diagnoses, based on the clinical criteria established by the ICHD $^9$  (Figure). The research project was approved by the Ethics in Research Committee (n $^\circ$  1.102.470).

#### **RESULTS**

## **Selection of CH patients**

In the screening carried out by the professionals of the Family Health Strategy, a total of 620 questionnaires were completed. The researchers contacted the interviewees by telephone and subsequently made a brief assessment of the interviewees at the hospital, according to the clinical criteria established by the ICHD. As a result, only 39 individuals presented with all the objective clinical conditions of CH patients, and were referred to a neurologist. After the specialist's evaluation, only 15 patients received a diagnosis of CH, representing a prevalence of 0.0414%; or 41.4 cases in 100,000 inhabitants. The remaining 24 patients were diagnosed with other types of primary headache.

# **Characteristics of the CH patients**

Regarding the 15 individuals diagnosed with CH, there was a predominance of males, 87% (95%CI; 69.5–104), in

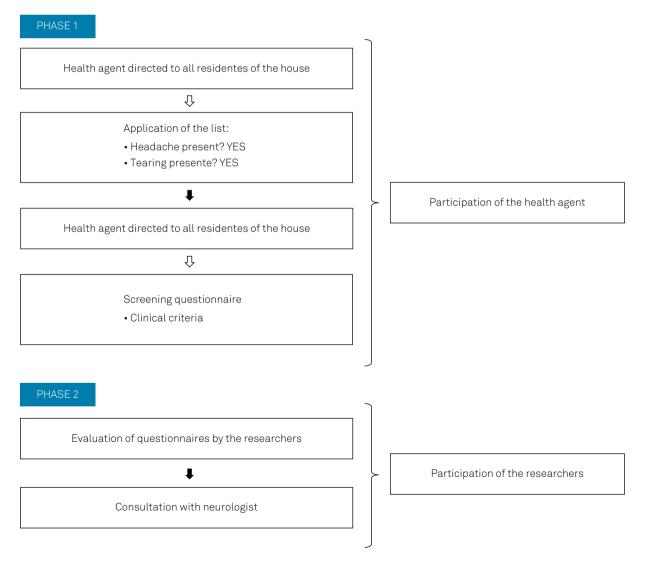


Figure. Flowchart.

relation to females, 13% (95%CI; 0–30.5). Regarding age, most patients were in the 35–45 year old group, followed by the 46-55 year old (13%) and 56-65 year old (33%) age groups. The weighted average and median of the ages were 48.8 and 42 years, respectively. When we analyzed the marital status of these patients, there was also a predominance of married individuals (67%), followed by those living together (27%) and those who were divorced (7%). Eight of the 15 patients (53%) with CH did not know about the diagnosis of CH.

As regards education, most of the patients had incomplete elementary schooling (40%), followed by complete elementary education (20%), high school (27%) and college (13%). Regarding income, the average was 2.2 minimum wages.

### DISCUSSION

The composition of the study population was an important feature and one of the difficulties in performing the research, as epidemiologic studies carried out in a primary health care center do not always reflect the reality of the prevalence and the impact of CH in the community. However, considering the quantitative aspect of the composition of this sample, it is possible to regard it as representative.

**Table 1.** Sociodemographic characteristics of patients diagnosed with cluster headache.

Variables	n	%
Gender		
Female	2	13.33
Male	13	86.67
Age (age group)		
35-45	8	53.34
46-55	2	13.33
56-65	5	33.33
Marital status		
Married	10	66.67
Living together	4	26.67
Divorced	1	6.66
Education		
Incomplete elementary education	6	40.00
Complete elementary education	3	20.00
High school	4	26.67
College	2	13.33
Income (minimum wage)		
No income	1	6.67
One	3	20.00
Two	7	46.67
Three	2	13.33
Five	2	13.33

The data collection method was by face-to-face structured interviews of adults of both sexes, a method with important advantages when compared with telephone or electronic interviews, or the self-completion questionnaire. In addition, the clinical interview conducted by a headache expert, which was considered as the gold standard for the performance of this study, enabled correct diagnoses, considering the subtle clinical differences among primary headaches<sup>10</sup>.

Despite its limitations, this study is the first epidemiologic CH study with classical and accepted methodology carried out in this country.

The lifetime prevalence of CH was 0.0414%, or 41.4 cases in 100,000 inhabitants in the city of Barbacena, Brazil. The study closest to the prevalence found in Barbacena was carried out in Ethiopia in 1993, in a sample of 15,500 individuals, with a prevalence of 32 cases/100,000 inhabitants<sup>11</sup>. The following studies found a greater prevalence of CH in their populations: in Sweden between 1935-1958, with a sample of 31,750 showing a lifetime prevalence of 144 cases/100,000 inhabitants<sup>12</sup>, and in 1975–1976 with a sample of 9,803 males aged 18 or older with a lifetime prevalence of 92/100,000<sup>13</sup>; in the Republic of San Marino in 1985, with a sample of 21,792 people and a prevalence of 69 cases/100,000 inhabitants<sup>14</sup>, and in 1999, with a sample of 26,628 people and lifetime prevalence of 70/100,000 inhabitants<sup>15</sup>; in Porto (Portugal) in 1992, with a sample of 2,008 people and lifetime prevalence of 100 cases/100,000 inhabitants<sup>16</sup>; in Germany in 2004, in Essen with a sample of 3,336 people and prevalence of 119/100,00017, and in 2005, in Dortmund with a sample of 1,312 people and prevalence of 150/100,000<sup>18</sup>; in Glostrup (Denmark) in 1989, with a sample of 740 people and lifetime prevalence of 135/100,000<sup>19</sup>; in Parma (Italy) in 2002, with a sample of 7,522 people and lifetime prevalence of 279 cases/100,000 inhabitants<sup>20</sup>; finally, in Vaga (Norway) in 1995, with a sample of 1,838 people and lifetime prevalence of 381 cases/100,000 inhabitants<sup>21</sup>.

The data in Table 2 allows for a better comparison of the prevalence found in these studies.

Upon assessing the sample of our study regarding sex, we found that 87% were male, with a male/female ratio of 13:2. The data confirms the literature, according to which the greater prevalence of CH was in males<sup>5,6,22</sup>.

As a national reference, a study carried out in  $2015^{23}$ , using an electronic questionnaire (n = 658) completed by the patients with probable CH, confirmed the diagnosis of 324 cases in Brazil and established a clinical and sociodemographic profile of CH patients. The study showed a greater occurrence in men (283, 73.1%) than in women (104, 26.9%) giving a ratio of 2.7:1; with an average age of 39.3 years, which reinforces the data found in the present study. Note that in the 2015 study<sup>23</sup>, the entry criterion was "individuals who have accessed a certain website".

This study had a larger sample than the aforementioned studies. However, due to the clear difference between the proposed methodologies, the study population and the diagnostic

Table 2. List of references, countries, year of publication, population and prevalence found in the studies.

Reference #	Country	Year	Population	Prevalence
11	Ethiopia	1992-93	15,5	32/100,000
Present study	Brazil	2016	36,145	41.4 /100,000
14	Rep. of San Marino	1985	21,792	69/100,000
15	Rep. of San Marino	1999	26,628	70/100,000
13	Sweden	1975-76	9,803	92/100,000
16	Portugal	1992	2,008	100/100,000
17	Germany	2004	3,336	119/100,000
19	Denmark	1989	740	135/100,000
12	Sweden	1935-58	31,75	144/100,000
18	Germany	2005	1,312	150/100,000
20	Italy	2002-03	7,522	279/100,000
21	Norway	1995	1,838	381/100,000

Rep.: Republic.

criteria applied in the studies, there was difficulty in comparing the results of the prevalence of CH, reaffirming the conclusion by Fischera<sup>6</sup> that establishing prevalence is difficult.

It takes two years, on average, for a patient with CH to receive a correct diagnosis. In this article, we are evaluated the effectiveness of the Brazilian health system and its employees in screening the population to identify patients with CH. A substantial number of the CH patients identified in the present study (> 50%) did not know about their diagnosis of CH and, therefore, had not received adequate treatment. This is a fact of utmost importance, indicating that the public health system, using a simple questionnaire, which identified individuals with strictly unilateral headache and tearing, was able to give patients with "probable" CH access

to a headache specialist, as they may not have utilized health care services as much as other chronic afflictions with higher morbidity and mortality rates<sup>24</sup>.

Quite possibly, for various reasons, some individuals with CH may not have been identified in the present study. For example, a small proportion of CH patients do not report tearing, or present with agitation without autonomic symptomatology. However, this appears to be infrequent.

In conclusion, this study helped define the prevalence of CH in Brazil, which, although being considered a rare disorder, has a big impact on the quality of life of individuals, justifying the importance of the study. The prevalence of CH found in the sample of 36,145 inhabitants in the city of Barbacena/MG was 0.04%, or 41.4 per 100,000 inhabitants.

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