EUROPEAN HEADACHE ALLIANCE

CH
special interest
group

SURVEY ON ACCESS TO HEALTHCARE FOR CLUSTER HEADACHE (CH) PATIENTS IN EUROPE

Introduction

This survey is about the access to healthcare for Cluster Headache patients in EU countries.
Cluster headache (CH) is a quasi-rare (prevalence 1:1000) excruciating form of primary headache, characterized by recurrent unilateral, short attacks of very severe headache, accompanied by autonomic symptoms/signs (i.e. rhinorrhea/nasal congestion, lacrimation, conjunctival injection) and restlessness. These attacks most commonly appear in clusters i.e. active periods separated by pain-free remission periods (1).
CH is considered the most severe pain condition that afflicts humans (2). Patients usually describe the pain as "having a red hot poker forced through my eye", an "agony" , "a trip to hell you can't control" and they report that the intensity is so extreme it is unlike anything they have ever experienced. The severity of pain has earned it the nickname "**suicide headache**" and a suicidal risk exists in this condition (in a recent survey 55% of CH patients reported suicidal thoughts, 3)
Due to the extraordinary severity of pain **the personal burden related to CH** comprising unemployment (more than 1/3 of the chronic patients has lost their job !), psychiatric complaints, poor quality of life , socio-relational and familial restrictions **is enormous (4).**
Despite the diagnosis of CH being very simple, and rapid and effective treatments for alleviating CH pain available, **CH is largely under-recognised and under-treated**. Average diagnostic delay is of 5.3 years and this delay prevents the access to appropriate therapies. It has been estimated that 2/3 of patients never receive the correct treatment(5). Mismanagement of CH extends beyond missing the diagnosis and the prescription of the right treatments. In most of the EU, effective treatments such as oxygen or sumatripan injections are not reimbursed or are reimbursed with captious restrictions. In most of the EU, medico-legal protection for CH sufferers is not guaranteed, as well as fast access to a headache specialist without waiting list or any form of psychological support. CH patients are concerned about access barriers met in obtaining high quality affordable healthcare increasing the burden of the disease itself into a considerably reduced quality of life.

The European Headache Alliance Cluster Headache Special Interest Group (EHA CHSIG) involved its member organizations into a survey to find out more about the experience of access to healthcare from the CH patients' view across the EU.

On February 2018 a large-scale online survey was launched. The objective was **to identify potential challenges in the area of access to healthcare for patients and to inform policy-making and ensure that future the advocacy actions are developed with consideration of the special need of CH patients**

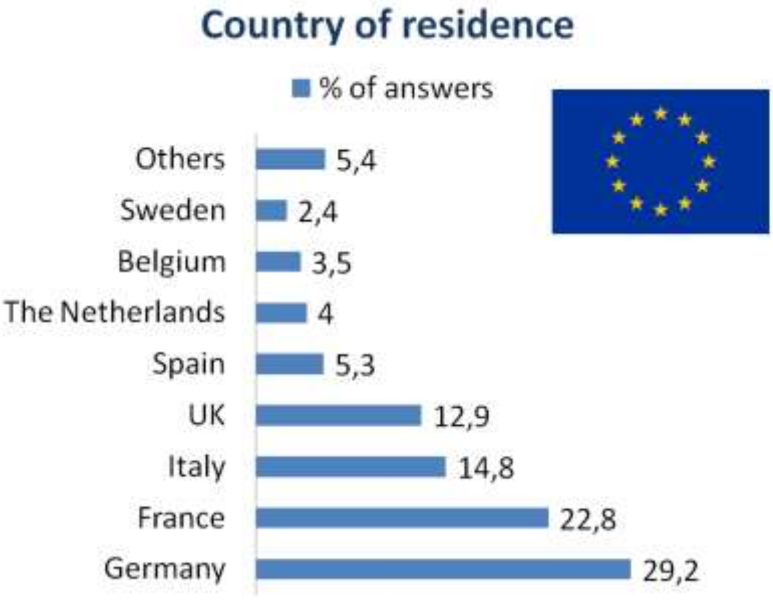
Methodology

Access to healthcare has been defined accordingly to the European Patients Forum (EPF) patient-centred perspective that considered it as a multidimensional concept (6). This definition is based on **5 As - Adequate, Accessible, Affordable, Appropriate, and Available - as the defining aspects of access**. The survey used in this study was an adaptation of the EPF developed survey and explored these 5 dimensions of access. EHACH SIG proposed it in six languages: English, German, French, Spanish, Italian and Flemish.

The study was carried out online through SurveyMonkey and had a very large participation.

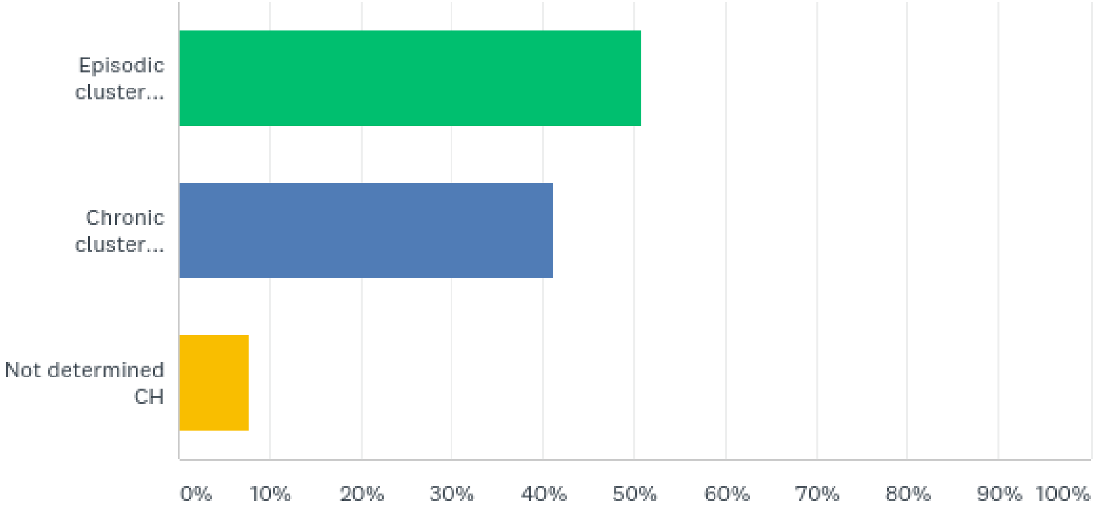
In one month we received **2057 responses from 10 countries** (all member states who joined the EU before 2004).

Figure 1. Percentage of respondents per country



55.5 % of the participants were male(the male to female ratio 1.27 is lower than that reported in epidemiological studies on CH and is conditioned by having completed the recruitment through patients'associations members) . 41.5% suffered for chronic CH (figure 2)

Figure 2 Percentage of CH subgroup diagnosis



32% rated their health as poor/quite poor (it was 49% in the Chronic CH group)

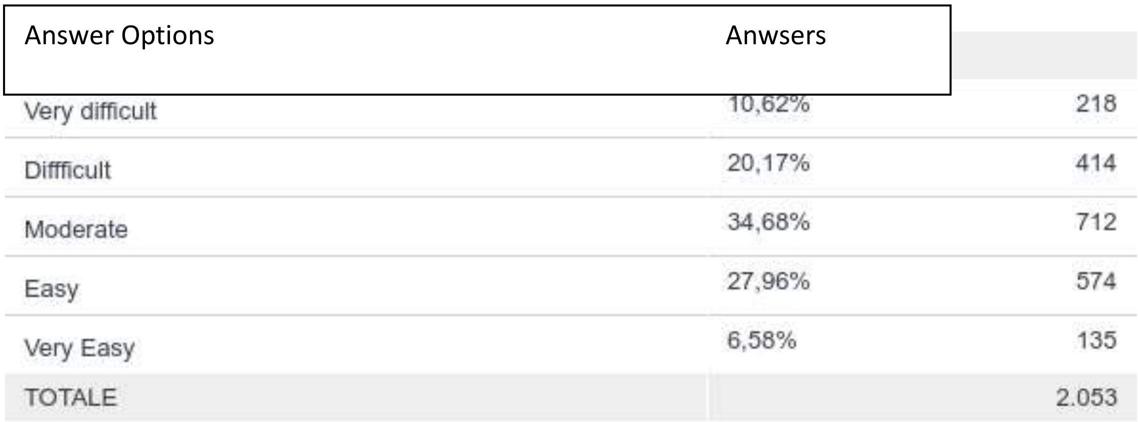
This is **the largest population of CH patients ever surveyed in Europe**

WHAT IS THE SITUATION ?

AVAILABILITY

31% of the CH patients rated as difficult or very difficult to obtain the healthcare services they need (Table 1).

Table 1. Thinking of access overall, how difficult or easy was it to actually obtain the healthcare services you needed (medicines, diagnostic tests, doctor visits, etc) for your cluster headache within the past 12 months ?



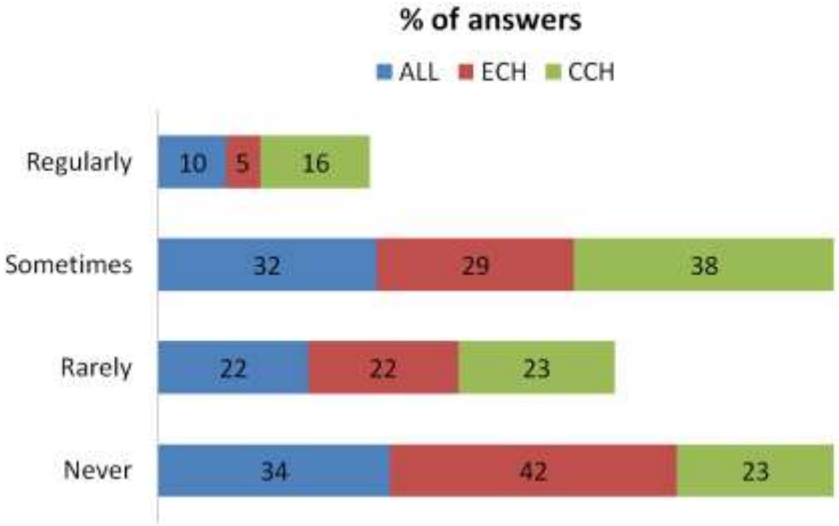
Answer Options	Anwsers	
Very difficult	10,62%	218
Diffficult	20,17%	414
Moderate	34,68%	712
Easy	27,96%	574
Very Easy	6,58%	135
TOTALE		2.053

Only the information on available healthcare for CH coming from websites (61%) and patients'associations (54%) was rated as good/very good by the majority of the responders that were very dissatisfied about the one provided by institutional sources as doctors (28.5 rated as good/very good) , pharmacies (15% of approval), TV/media and public health authorities (2.5% and 3.5% of approval, respectively)

AFFORDABILITY

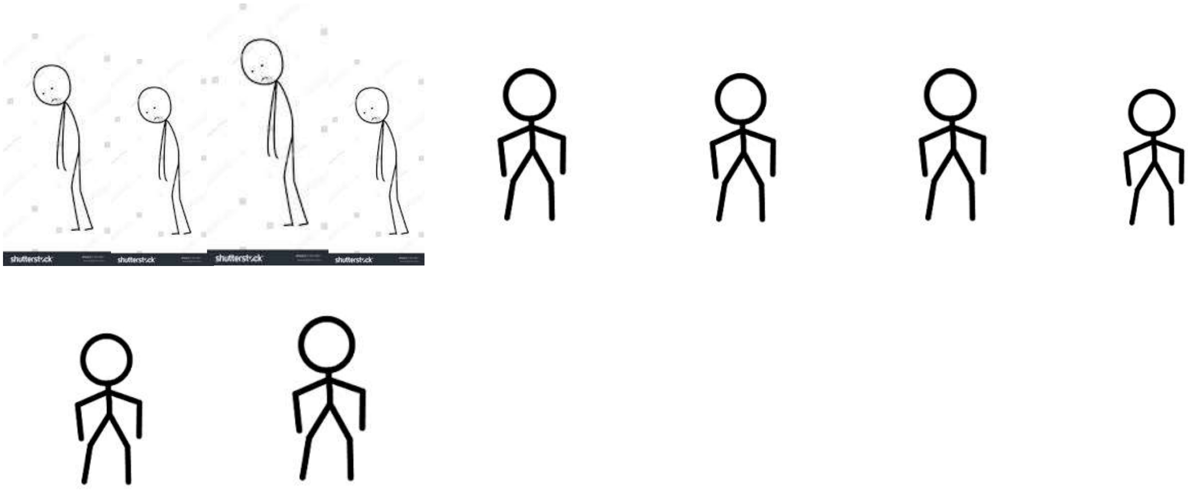
Too many CH patients in Europe experience financial difficulties as the result of spending on healthcare for CH (43% sometimes or regularly, figure 3) especially **among chronic patients (54.5% reported financial hardship at least sometimes**).

Figure 3. Do you experience financial difficulties as a result of spending on healthcare for your headache?



When asked more specifically about the ability to afford specific services, responses varied importantly depending on the service concerned. **For medicines and other treatments only 6 out of 10 patients declared they can afford always/very often** the cost while results **indicated 57% for headache specialists**, **33% for diagnostic exams and only 25% for specialized healthcare providers** (psychologist, physiotherapist and complementary therapies providers).

Figure 4 Only 60% of CH patients across Europe can afford always/ often the cost of medicines

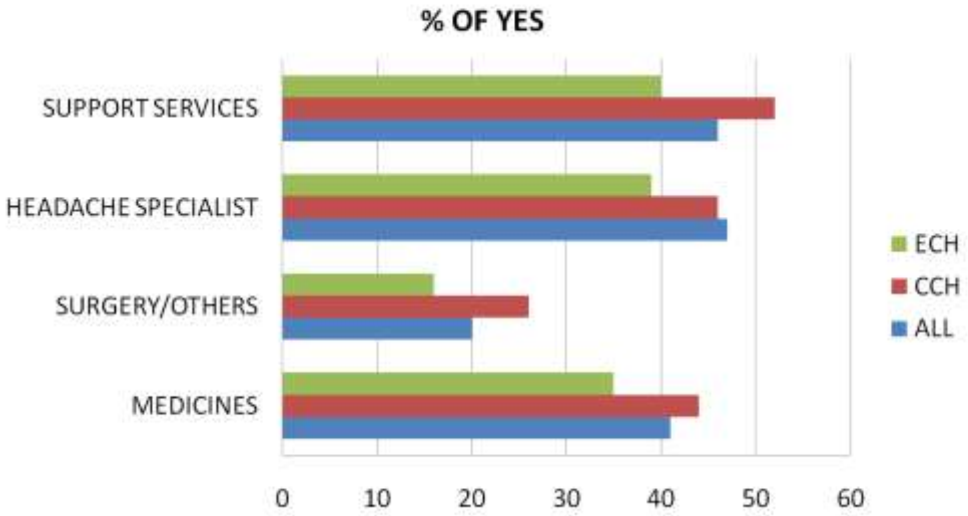


When asked if their **healthcare costs are sufficiently covered by the healthcare system 1 out of 3 CH patients disagreed.**

ACCESSIBILITY

Almost half of the respondents reported delays in accessing key services as headache specialists (47%) medicines (43%) and support from social services or other forms of welfare protection (46%). The difficulty in accessing healthcare services were significantly greater for chronic CH patients (Figure 5).

Figure 5. Over the past 12 months, have you experienced a significant delay in accessing the following services



ADEQUACY

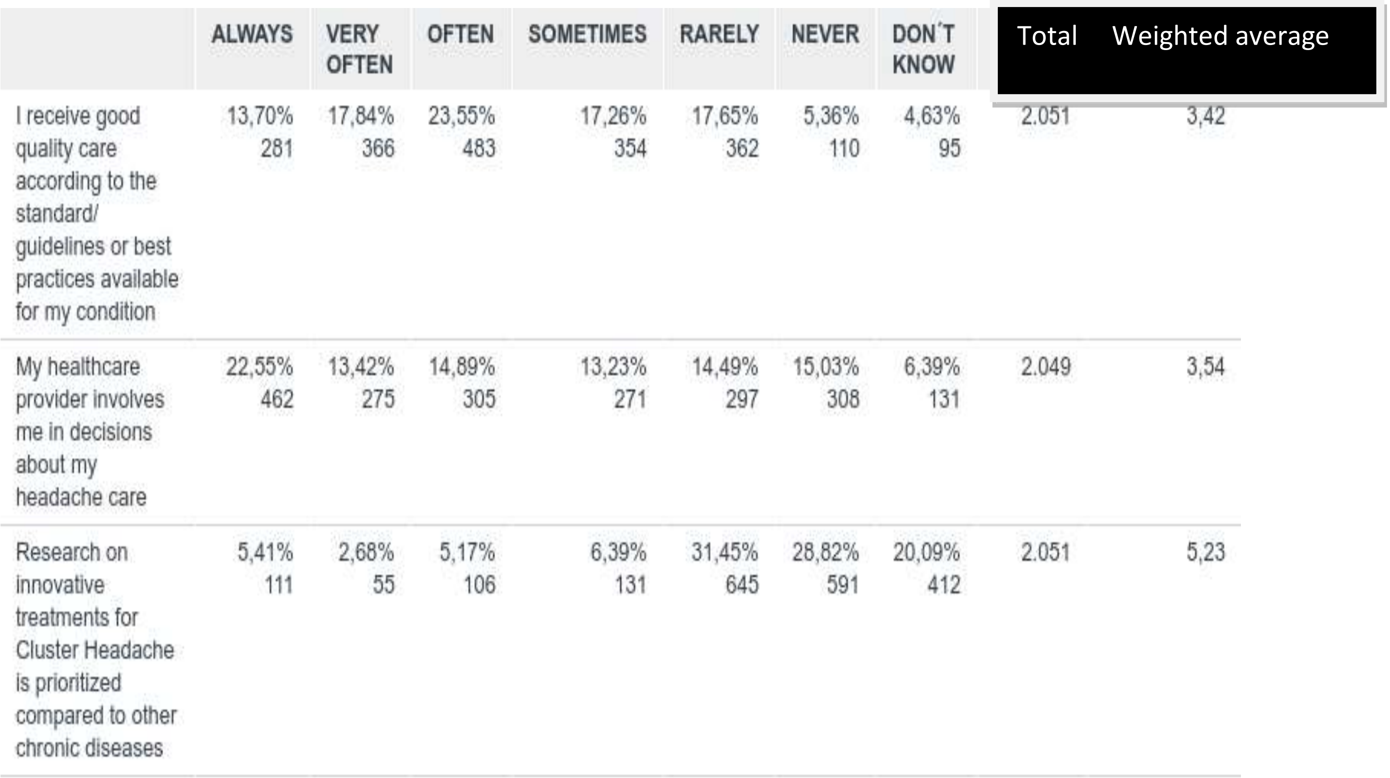
The survey demonstrated that quality of healthcare for CH in Europe is not perceived as optimal and aspects of patient-centred care are not implemented (Table 2).

When **asked if they received good quality care according to the standard/guidelines best practice available for their condition only 30% indicated it was the case always/very often**

37% reported to be never /rarely involved in decisions regarding their care by physicians

Finally an amazing **61% indicated that never/rarely the research on innovative treatments for CH is prioritized compared to other chronic disorders**

Table 2. Would you agree with the following statement on the quality of care for your cluster headache?

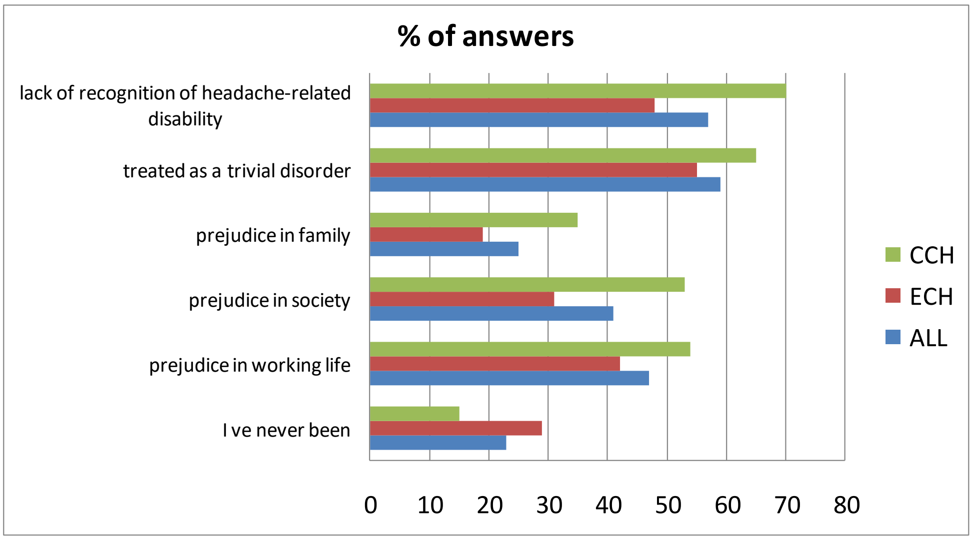


	ALWAYS	VERY OFTEN	OFTEN	SOMETIMES	RARELY	NEVER	DON´T KNOW	Total	Weighted average
I receive good quality care according to the standard/ guidelines or best practices available for my condition	13,70% 281	17,84% 366	23,55% 483	17,26% 354	17,65% 362	5,36% 110	4,63% 95	2.051	3,42
My healthcare provider involves me in decisions about my headache care	22,55% 462	13,42% 275	14,89% 305	13,23% 271	14,49% 297	15,03% 308	6,39% 131	2.049	3,54
Research on innovative treatments for Cluster Headache is prioritized compared to other chronic diseases	5,41% 111	2,68% 55	5,17% 106	6,39% 131	31,45% 645	28,82% 591	20,09% 412	2.051	5,23

APPROPRIATENESS

The majority of CH patients (76%, 85% in the chronic CH group) reported they experienced discrimination for their CH.. The main challenges reported by H patients were "to be treated as having a trivial disorders" (59%) and "the lack of acknowledgement of Ch-related disability" (57%, 70% in the chronic H group). Almost half of the respondents (47%) reported discrimination in working life as prejudice/negative attitudes (Figure 7).

Figure 7 Have you ever been stigmatized or discriminated against because of your cluster headache? What kind of discrimination have you experienced?



RECCOMENDATIONS TO ENHANCE ACCESS TO HEALTHCARE FOR PEOPLE WITH CLUSTER HEADACHE

The survey's results point to fundamental challenges to tackle and key areas of action for decision makers at EU and national level to address in order to ensure patients with Cluster Headache have access to high quality, affordable healthcare across the European Union.

1. **Ensuring affordability of healthcare** by:

- adopting measures to ensure support and appropriate healthcare to patients group most vulnerable to financial hardship as a result of healthcare costs (e.g. low income, occupational disability, multimorbidity)
- meaningful patients'organisations involvement in the decision making processes of what services should be covered in order to ensure that CH is appropriately recognized by healthcare system
- put in place appropriate strategy to enhance the access to innovative medicines

2. **Tackling organizational challenges** by:

- training healthcare professionals on CH patients' peculiar needs
- training healthcare on communication with chronic pain patients and on human rights
- reducing bureaucracy and promoting better coordination and delivery of care (e.g. timely access to headache specialists, medicine or social support; reduction of geographical and national differences)
- acknowledging that chronic CH is a disabling disorder

3. **Ensuring appropriate resources are invested efficiently in healthcare services for CH**

4. **Recognising patients are part of the solution and ensuring patients' perspective on access to healthcare is collected and used**

5. **Promoting actions to raise awareness about this and other painful disorders including high quality and transparent information throughout different media**

References

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