AT LESSONS FROM THE EXPERT PATIENTS

Advices for the physicians to improve their care of Cluster Headache patients

The 7 commandments

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European Civic Prize Award on Chronic Pain

(category: Patient Empowerment)

A simple idea...... for a very complex problem

- When Health Care fails to meet patients' needs the patients should be involved more actively in the decision making process
- In pain medicine patient's is an urgent need

A call to empowerment…

- Painful and psychiatric disorders are the top causes of years lost with disability and they are **not addressed in health policies**
- Scientists are good at producing numbers but they are not good at translating them into policy

Mean YLDs ×1000	Mean rank (95% UI)	1990 leading causes	2013 leading causes	Mean rank (95% UI)	Mean YLDs (×1000)	Median percentage change
46068	1·3 (1–2)	1 Low back pain	1 Low back pain	1·0 (1–1)	72318	57% (53 to 61)
40079	2·0 (1–3)	2 Iron-deficiency anaemia	2 Major depression	2·1 (2–4)	51784	53% (49 to 59)
33711	2·8 (1–4)	3 Major depression	3 Iron-deficiency anaemia	3·6 (2–6)	36663	−9% (−10 to −7)
22294	4·7 (4–6)	4 Neck pain	4 Neck pain	4·3 (3–6)	34348	54% (49 to 60)
21633	5·1 (3–7)	5 Other hearing loss	5 Other hearing loss	5·3 (3–9)	32580	51% (45 to 55)
19805	5·8 (4–8)	6 Migraine	6 Migraine	6·6 (3–10)	28898	46% (41 to 50)
17180	6·9 (4–9)	7 Anxiety disorders	7 Diabetes	6·7 (5–9)	29518	136% (127 to 144)
15151	7·9 (6–10)	8 COPD	8 COPD	7·8 (4–10)	26131	72% (67 to 79)
12672	9·5 (7–12)	9 Other musculoskeletal	9 Anxiety disorders	8·5 (5–10)	24356	42% (36 to 47)
12533	9·5 (8–11)	10 Diabetes	10 Other musculoskeletal	9·2 (7–10)	22644	79% (75 to 83)
10337	11·6 (10–13)	11 Falls	11 Schizophrenia	11·5 (11–15)	15204	52% (50 to 54)
9995	12·0 (9–16)	12 Schizophrenia	12 Falls	12·7 (12–14)	12818	23% (14 to 35)
8048	14·7 (12–19)	13 Asthma	13 Osteoarthritis	12·8 (11–15)	12811	75% (73 to 78)
7831	15·5 (10–23)	14 Refraction and accommodation	14 Refraction and accommodation	15·5 (11–22)	11257	44% (40 to 47)
7362	16·2 (13–20)	15 Diarrhoeal diseases	15 Asthma	16·1 (12–21)	10596	32% (29 to 35)
7307	16·4 (14–19)	16 Osteoarthritis	16 Dysthymia	17·4 (14–21)	9849	55% (52 to 57)
6780	18·5 (14–24)	17 Dermatitis	17 Bipolar disorder	17·5 (12–25)	9911	49% (46 to 53)
7491	18·8 (8–36)	18 War and legal intervention	18 Medication overuse headache	17·8 (12–27)	9846	120% (109 to 134)
6643	18·8 (13–26)	19 Bipolar disorder	19 Other mental and substance	18·5 (14–24)	9257	52% (50 to 54)
6368	19·7 (15–24)	20 Dysthymia	20 Dermatitis	18·8 (15–25)	9278	37% (35 to 39)
6076	20·6 (15–25)	21 Other mental and substance	21 Alzheimer's disease	22·2 (18–26)	7774	92% (85 to 99)
5699	22·1 (17–26)	22 Alcohol use disorders	22 Alcohol use disorders	23·0 (18–28)	7654	34% (32 to 37)
5827	22·9 (12–38)	23 Acne vulgaris	23 Epilepsy	23·2 (18–30)	7544	41% (28 to 57)
5365	23·5 (18–29)	24 Epilepsy	24 Edentulism	25·9 (21–31)	6856	46% (43 to 48)
5288	23·9 (17–31)	25 Conduct disorder	25 Diarrhoeal diseases	26·1 (23–30)	6854	−7% (−9 to −5)
		26 Edentulism	26 Acne vulgaris			
		27 Medication overuse headache	29 Conduct disorder			
		28 Alzheimer's disease	[illegible] War and legal intervention			

Communicable, maternal, neonatal, and nutritional disorders
Non-communicable diseases
Injuries

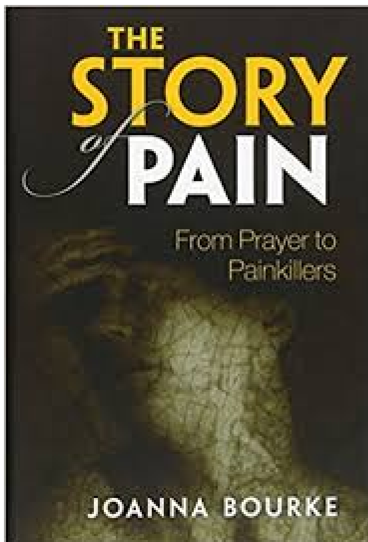
I have a ~~dream~~ …suspect

(..bad time for dreamers good time for mistrustful…)

- "Wishing that mental illness would not exist has led our policy-makers to shape a health-care system as if it did not exist" (Paul Appelbaum, APA, 2002)
- "Wishing that **pain** would not exist has led our policy-makers to shape a health-care system as if it did not exist " (P.Rossi, Headache, a possible life, 2017)

About neglecting pain (cultural and attitudinal barriers)

"The merest schoolgirl, when she falls in love, has Shakespeare and Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language itself runs dry" (V.Woolf, "On being ill").



- "Pain defies language but witnesses to pain don't want to hear….pain disrupts biographies…"
- "In the post-modern society pain has become the evil to eradicate. Endurance is perverse rather than praiseworthy and patients narrative an obstacle that prevent treatment…"

“**The symptom-based approach** is the most important barrier preventing an appropriate care of pain “

An opioid epidemic is what happens when pain is treated only with pills

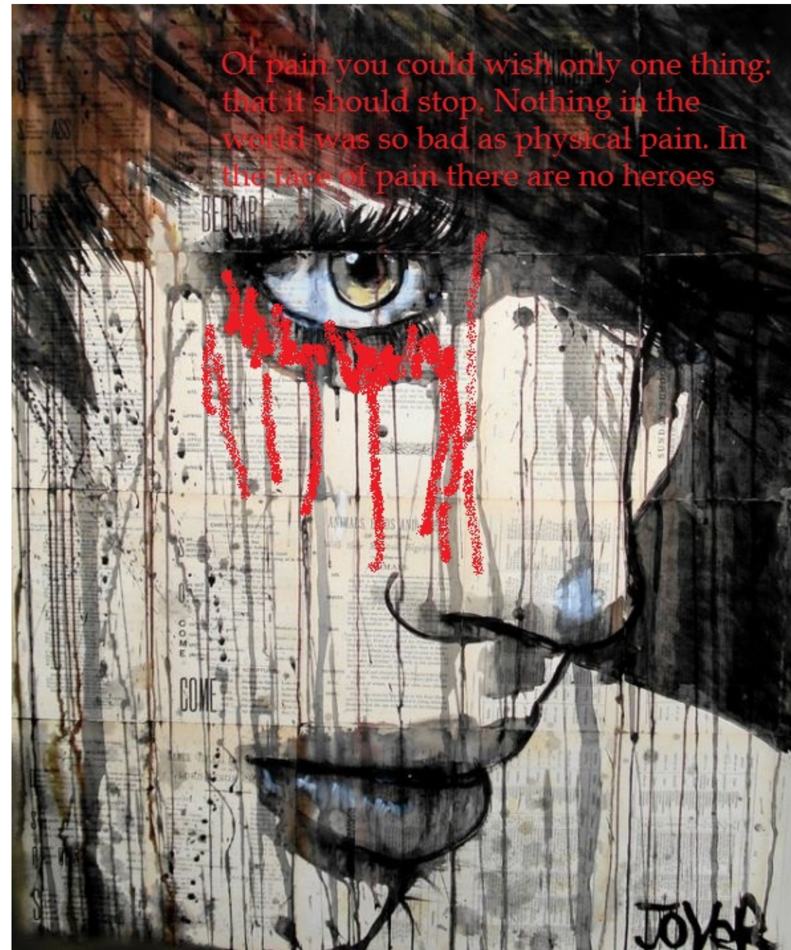
The Washington Post

K.Waloo, 2017 Pain a political History

About neglecting Cluster Headache

In the face of pain there are no heroes

An open letter to the MEPs (Cluster Headache Day 2017)



Making the Invisible Visible in Headache
Pain, Bruxelles 24-01-2017

The double drama of Cluster Headache patients

- 1°- the disease with its attacks of unbearable pain

- 2°- the difficulty in having access to high quality medical care, support, respect and acceptance

The pain of CH

- Arguably the most severe pain condition that afflicts humans (Nesbitt & Goadsby 2012)
- Suicide headache
- 1/3 of chronic CH patients has lost the job
- 60% of patients report an impact on his/her family (high rate of divorce, low rate of natality)
- High rate of psychiatric complaints
- ("*for CH patients days are made of fear of pain immersed in feelings of loneliness, impotence and frustration*" Palacios-Cena et al 2016)

The health care system neglecting CH

Joshi et al. The Journal of Headache and Pain (2017) 18:76
DOI 10.1186/s10194-017-0785-3

The Journal of Headache and Pain

RESEARCH ARTICLE Open Access

The comorbidity burden of patients with cluster headache: a population-based study

Shivang Joshi[1,2], Paul Rizzoli[3,4] and Elizabeth Loder[3,5*]

Joshi et al. The Journal of Headache and Pain (2017) 18:76 Page 7 of 9

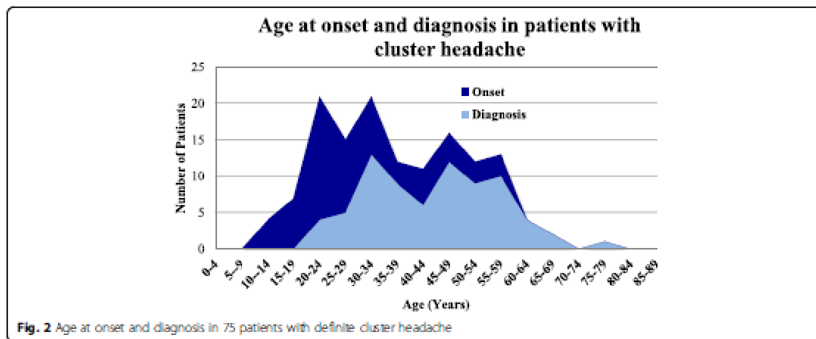
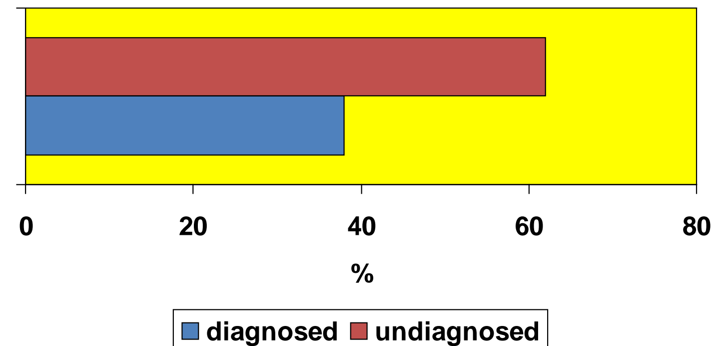


Fig. 2 Age at onset and diagnosis in 75 patients with definite cluster headache

Figure 2 illustrates the distribution of patients with Definite CH by self-reported age at onset of CH in comparison with age at the time of CH diagnosis. The average time from first appearance of symptoms to diagnosis was 12.7 years (range 1 to 51). Figure 3 shows the aver-

- The diagnostic delay is on average 6 years in clinical series (far higher in population-based studies)

Cluster headache prevalence in the Italian general population (Torelli et al., 2005)



The health care system neglecting CH

- 2/3 never receive the corrects treatments
- Additional problems exist in access to care psychological suppport and medico-legal protection

Availability of effective evidence-based symptomatic treatments for cluster headache in the EU countries
A survey of the European Headache Alliance

P. Rossi (1,2), and Elena Ruiz De La Torre (2)

1) INI Grottaferrata, 2) European Headache Alliance, e-mail: paolo.rossi9079@gmail.com

•Availability of CH effective treatments resulted complete, restricted or lacking for 47%, 35.2% and 18% respectively of the CH European patients (Figure 1)

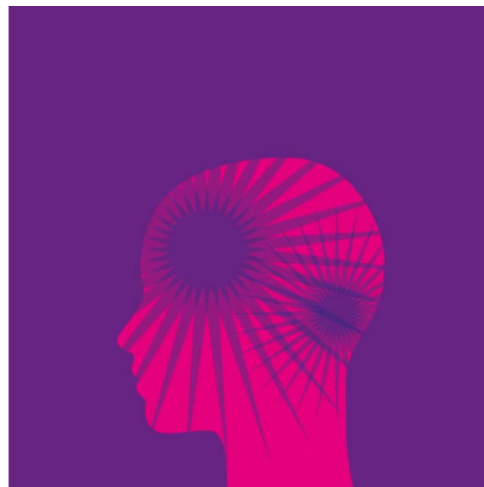
Figure 1 Availability of effective medication for cluster headache
Green smile= **complete**; both oxygen and sumatriptan s.c fully reimbursable and accessible
Orange smile= **restricted** *; partial reimbursment or inaccessibility of one between Oxy and Suma s.c
Red smile= **lacking**; both oxygen and sumatriptan s.c not reimbursable and not accessible

Conclusion: Based on this survey **only 47% of the EU population had an unrestricted access to CH effective treatments with unacceptable inequalities between eastern countries and the rest of Europe**. Headache societies and patients'associations should pressure European and national health authorities to improve the availability of effective

CURRENT HEALTHCARE ORGANIZATION IS UNABLE TO MEET CH PATIENTS' NEEDS AT A VERY BASIC LEVEL

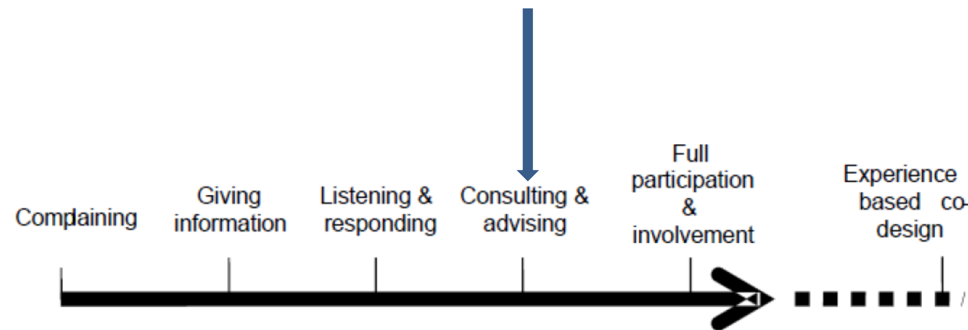
Priority

Moving from the dominant paradigm of Pain Medicine a **symptom-based approach** to a **patient-centred approach**



Aim of the study

- The aim of this study was to collect a list of recommendations from CH- Expert Patients for the physicians engaged in the CH management with the purpose to improve their ability in taking care of CH patients
- (Aiming at the highest level of patient's empowerment)

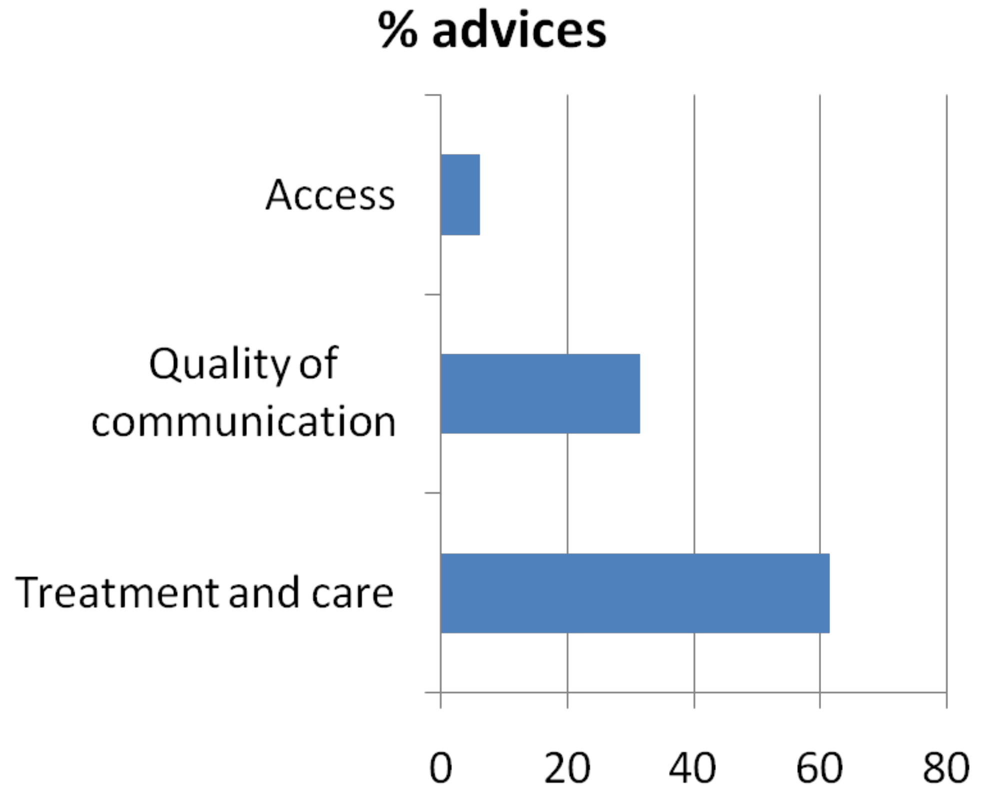


Methods

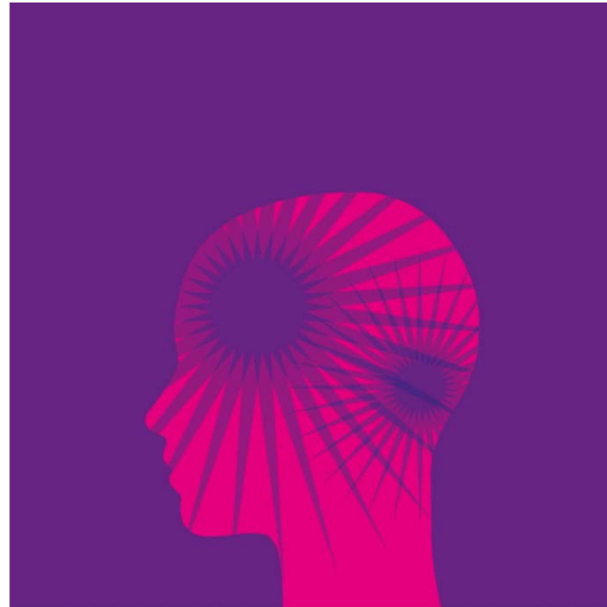
- Patients' association providing guide and support to CH sufferers in six European countries received a letter of invitation to join to the study on April 2014.
- Those CH groups who accepted to participate were requested to provide a list of recommendations and advices for the physicians engaged in the CH management from at least 5 EPs.
- Qualitative content analysis (2 independent reviewers)

Results

- 5 countries (SP, I, SWE, UK, NL)
- 25 EPs
- 83 advices
- 77% of the EP' advices could be grouped in 7 main recommendations
- No difference among countries



The 7 Commandments

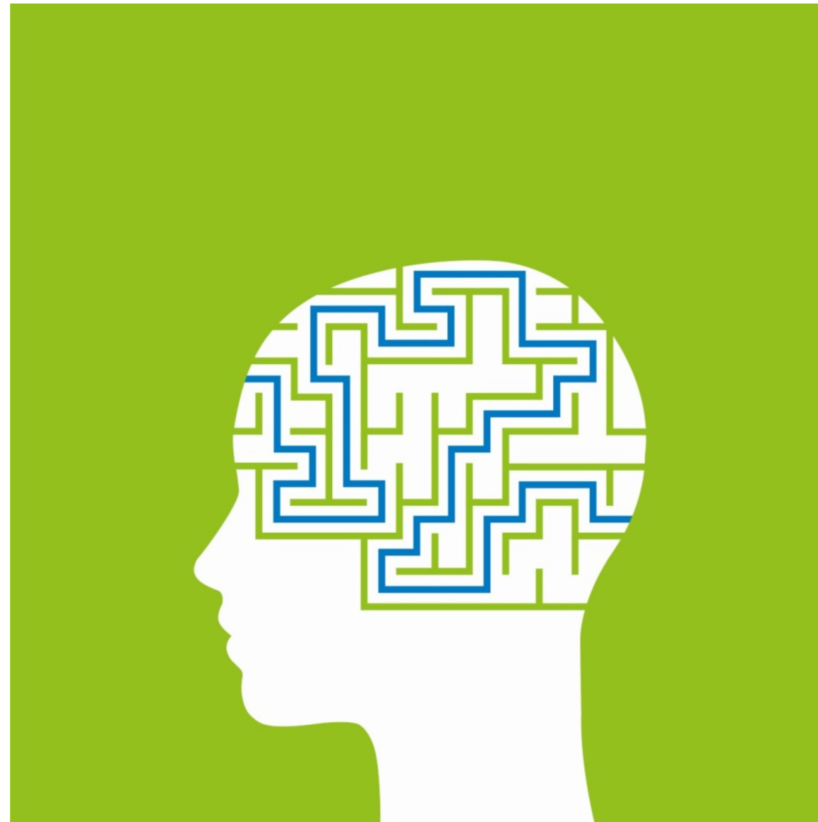


(graphic illustrations from)

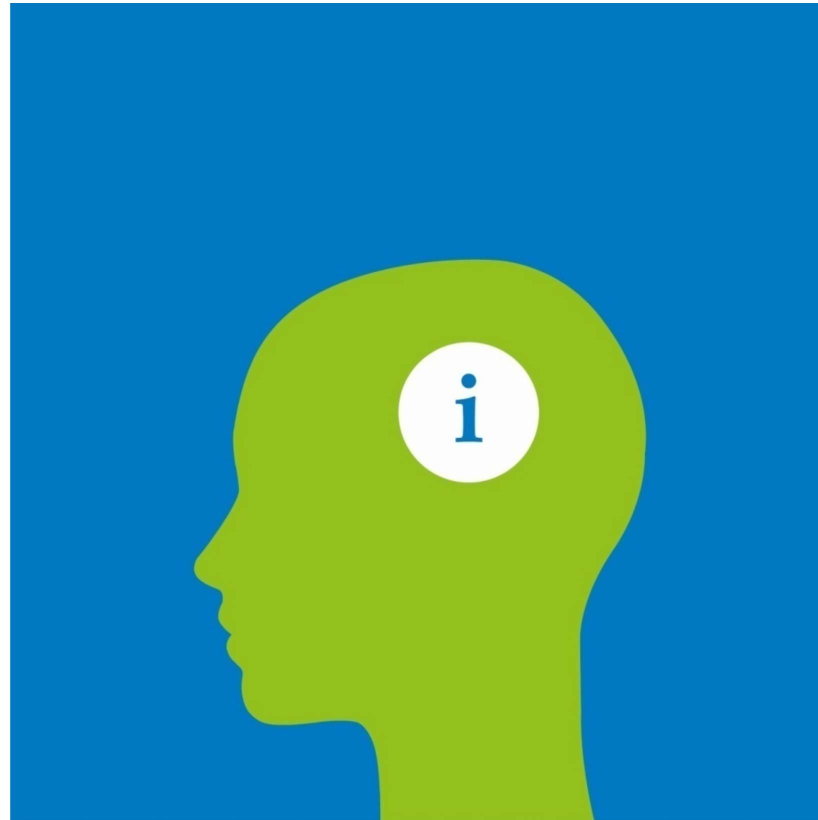
Carmen Monteil Cervantes

1st Prescribe the correct medication (sumatriptan s.c. and oxygen) at the right dose and in the right quantities

2nd Consider few clinical clues to make the diagnosis: it is very simple!
(and educate other doctors.....)



3rd Provide good information and be able to correct the misleading ones



4th Take patient seriously and listen to him/her to recognize his sufferings and that CH is a valid medical disorder that can have a significant impact on the person and support him

5th Be sensitive to the CH consequences on the patient's significant one and provide if necessary family and carer consultation

6th Suggest patient to not conceal and to be active in a patients' support group

7th Allow quick access for CH patients to headache specialists and be available if necessary

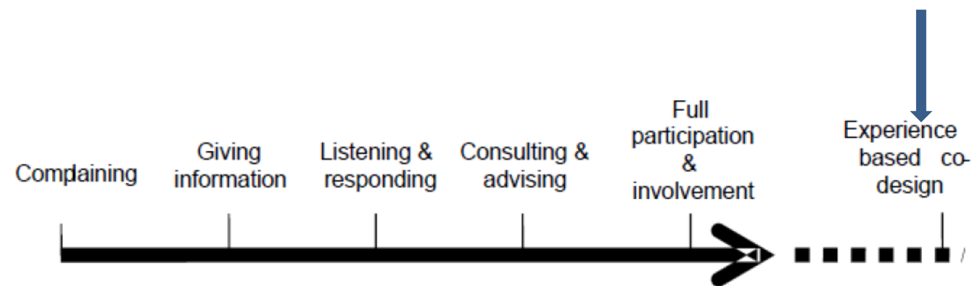
Comments

CH patients'unmet needs are independent from the perspective we are looking from and common to other pain disorders

CH EPs provided a list of pragmatic patient-centred changes in the health care assistance that can be realized with a little cultural end organizational effort

- *improving diagnostic delay, therapeutic appropriateness, burden recognition and access to care by educating physicians with few simple messages strenghtened by patients biographies*
- *empowering patients by recognizing the importance of education, expertise, experience (driven by patients' organization) and engagement*

THE CHALLENGE FOR THE FUTURE



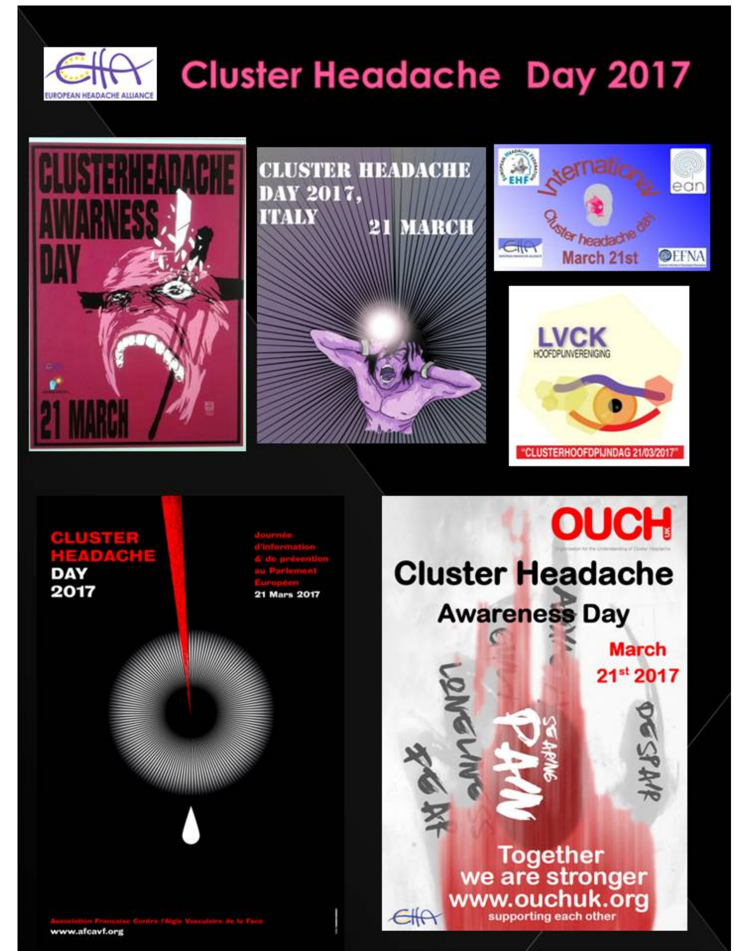
Actions started

EHA CH Special Interest Group

- 9 countries (B, FRA, GER/AUT, IRE, ITA, NL, SPA, UK)
- Reaching and mobilizing more than 10000 CH patients
- 3 request of participation to reasearch studies in few months

Actions started

Partnership with European Headache Federation and lobbying in the EP



Actions started

Partnership with national scientific societies for ad hoc seminars having EP as teachers

Il paziente al centro. Quello che i medici devono sapere sulla presa in cura dei pazienti affetti da Cefalea a Grappolo

What physicians must know about patient-centred care of Cluster Headache patients

Ono što liječnici moraju znati o zbrinjavanju usmjerenom prema bolesnike s cluster glavoboljom

Was Ärzte patienten-orientiert über Clusterkopfschmerz wissen müssen

Take home message: pain exists

two "safeguards" against pain are important:

- "trying to imagine people better and having laws that are not independent from our imagination“ (Elaine Scurry, 2006)