

Cluster Headache Is One of the Most Painful Human Conditions: Epidemiology of Cluster Headache and Probable Cluster Headache from a Large International Sample.

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Background

We recently published data on effectiveness of acute medications in cluster headache from a large international survey¹. The entire dataset included 152 questions, and here we report highlights from the larger dataset.

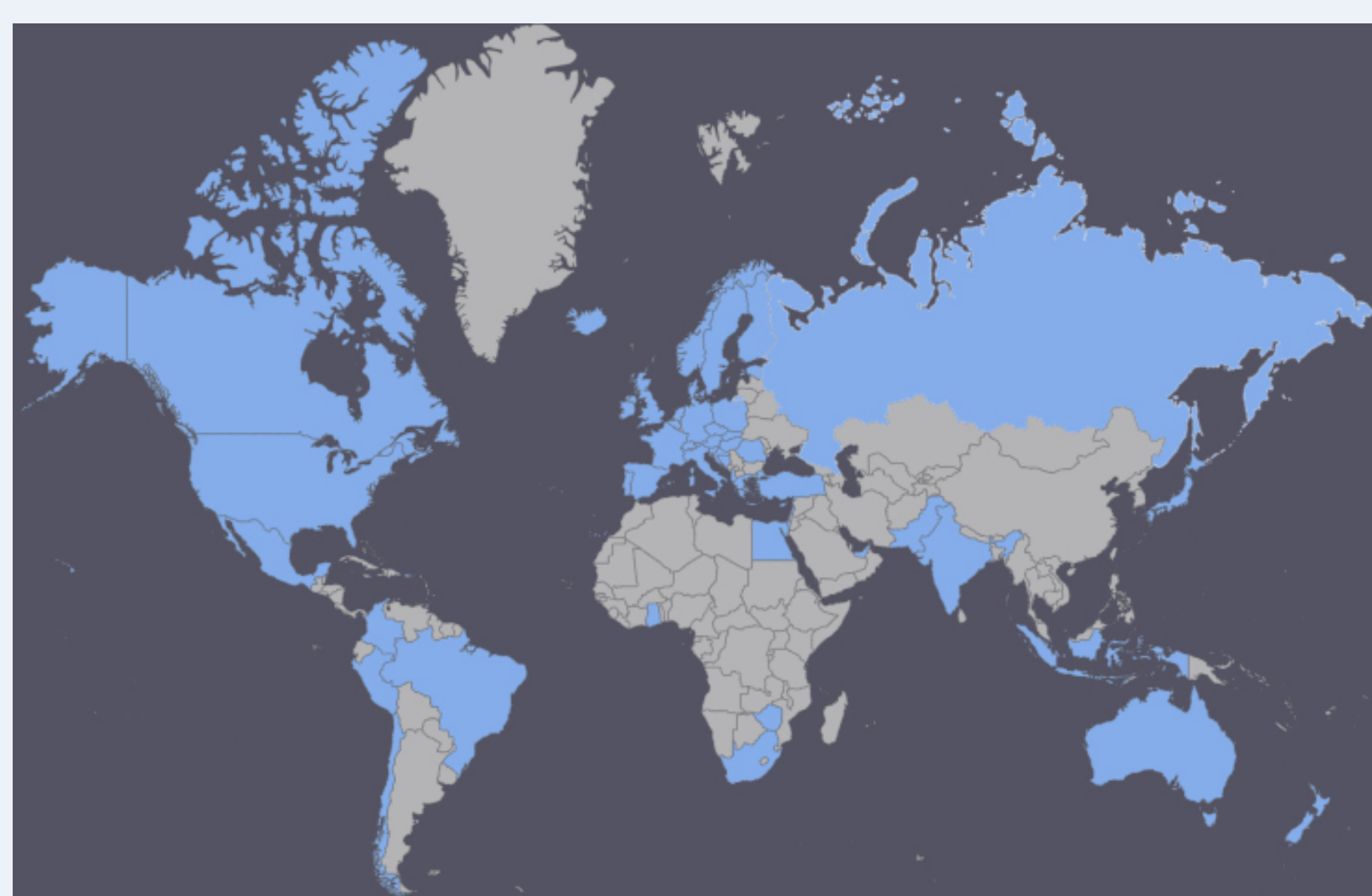
Our highlights explore several widely held notions of cluster headache:

- Cluster headache is anecdotally regarded by headache researchers as one of the most intense pains a human can experience²⁻³.
- Cluster headache typically has an onset between 20-40 years of age⁴⁻⁵
- Family history of cluster headache occurs but is rare⁶⁻⁷.

We also explore patients attitudes towards devices and a large subset of patients with probable cluster headache (i.e. fulfill all but one of the cluster headache criteria).

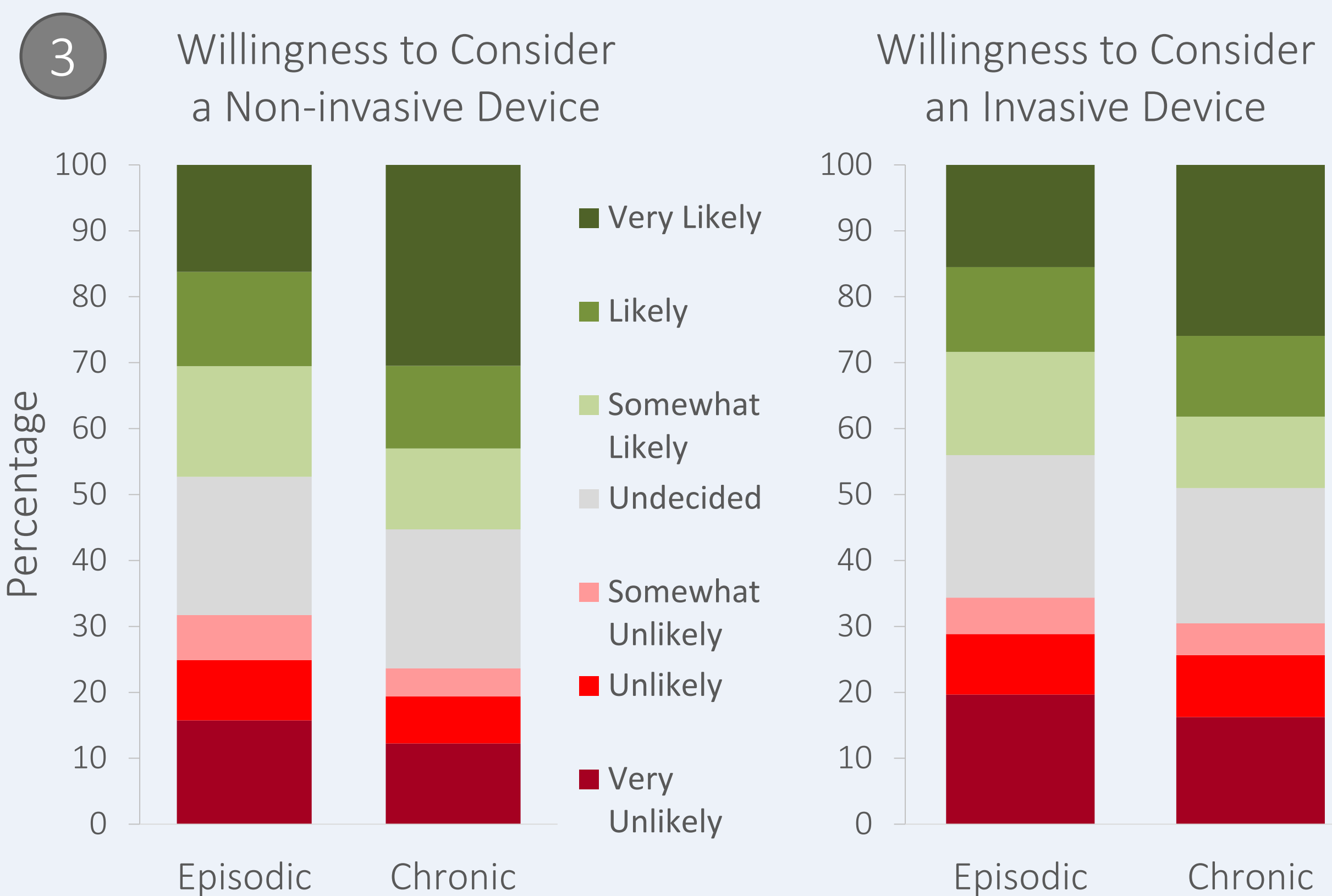
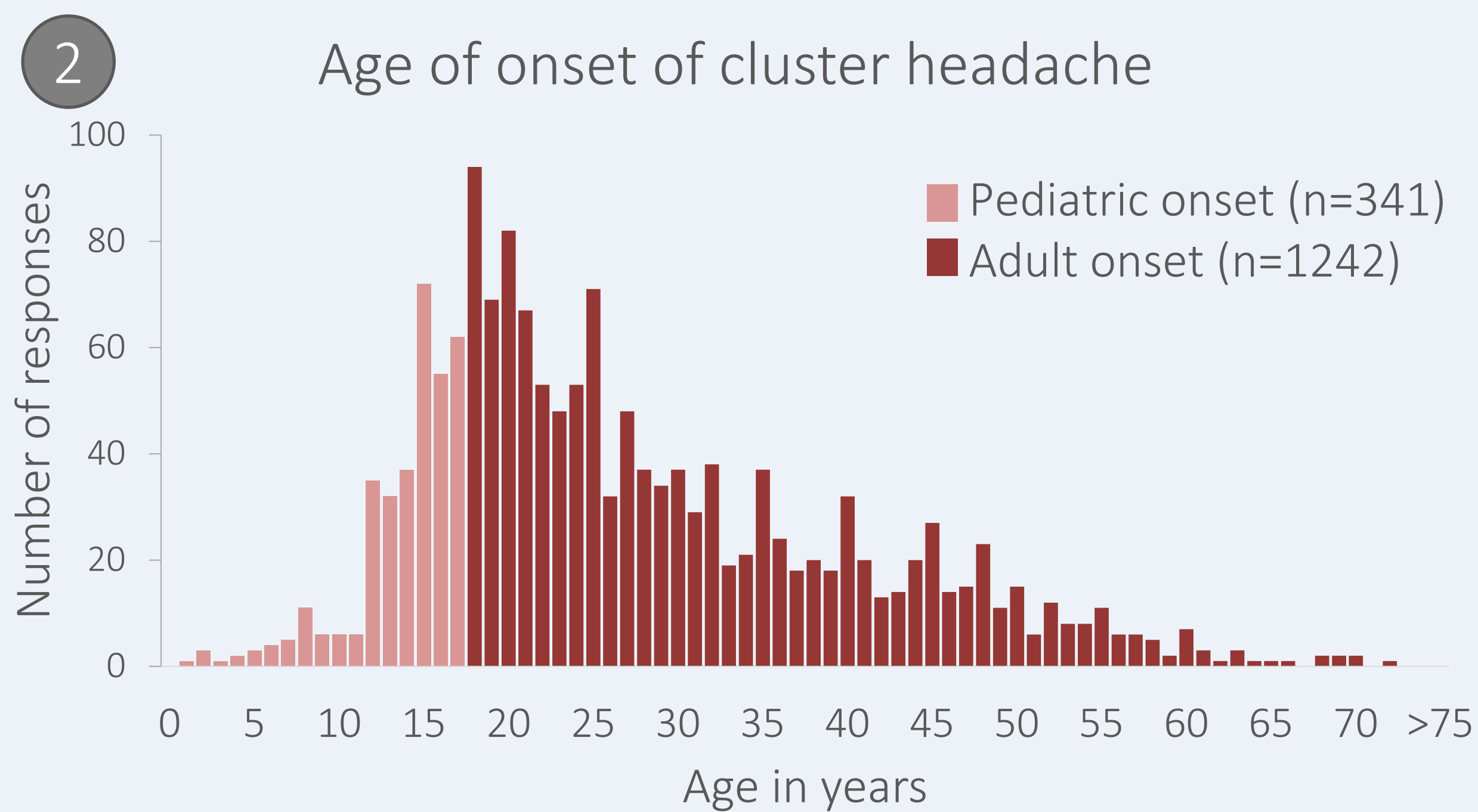
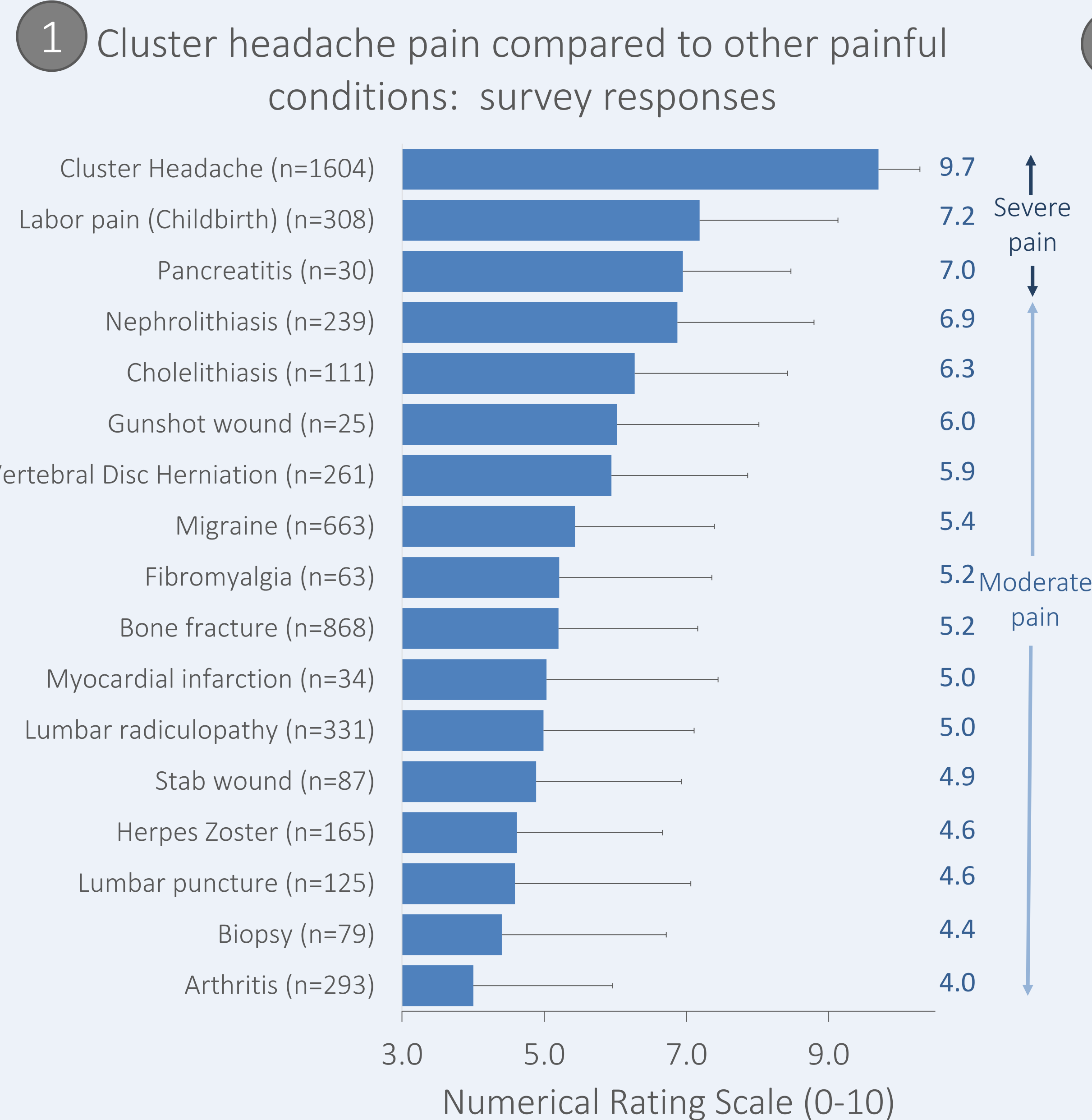
Methods

The Cluster Headache Questionnaire (CHQ) was an online survey filled out by participants between March 2016 and April 2018. Recruitment occurred via targeted online postings (International Headache Society website, Clusterbusters website, Reddit, GoogleAds). A total of 3251 respondents agreed to participate, and were filtered to 1604 definite cluster headache and 589 probable cluster headache respondents using the following criteria: age \geq 18, diagnosed with cluster headache by MD, completed 90% of survey in English, met ICHD3 criteria⁸ for cluster headache / probable cluster headache based on several targeted questions.



List of countries (in blue) with at least one survey response. Top 3: USA (60% of respondents), UK (14%), Canada (7%).

Results



Survey questions for devices
Non-invasive: 'I would be willing to consider an externally implantable device if it was shown to be safe and effective.'
Invasive: 'I would be willing to consider an internally implantable device if it was shown to be safe and effective.'

4 Table: definite vs probable cluster headache

	Cluster headache (n=1603)	Probable cluster headache (n=589)	P value
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Pain level (0-10)	9.70 \pm 0.58	9.56 \pm 1.12	* $<$.001
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Sex			
Male	69%	57%	* $=$.003
Female	31%	43%	

Age of onset	27.48 \pm 12.63	26.15 \pm 13.38	*.03
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Family history			
Positive	10%	12%	.13
Suspected	12%	14%	
None	77%	74%	

Migraine features			
Nausea / vomiting	27%	42%	* $<$.001
Light / noise sensitivity	50%	63%	* $<$.001
Worsening with activity	31%	48%	* $<$.001

Treatment effectiveness (completely + very effective)			
Triptans	54% (n=1193)	43% (n=411)	* $<$.001
Oxygen	54% (n=1082)	44% (n=356)	*.001
Corticosteroids	28% (n=753)	24% (n=282)	.20
Ca ²⁺ Ch Blockers	16% (n=987)	11% (n=339)	* $<$.001
Lithium	7% (n=304)	4% (n=121)	.72
Anticonvulsants	5% (n=586)	6% (n=252)	.97

Conclusions

1 This is the first large international study to compare the pain of cluster headache with other severely painful conditions. Cluster headache is as painful as previously surmised in the literature. Many extremely painful conditions are rated as moderate pain by cluster headache respondents.

2 Pediatric onset cluster headache occurred in almost a quarter of respondents (22%, 341/1585). A large increase occurs in teenagers. Recognition of younger onset may help reduce morbidity in this extremely painful disorder.

3 Approximately 50% of respondents would consider both invasive and non-invasive devices in the treatment of cluster headache.

4 Compared to cluster headache, probable cluster headache has more migraine features, less response to triptans/oxygen, and a similar response to most preventives.

Additionally, the rate of familial cluster headache is at least 10%, somewhat higher than prior studies.

References

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