

# Burden of disease in cluster headache patients and their relatives

Charly Gaul<sup>1</sup>, Mirjana Slijepcevic<sup>2</sup>, Janosch Fox<sup>3</sup>

<sup>1</sup> Headache Center Frankfurt, Germany

<sup>2</sup> Benedictus Hospital Feldafing, Germany

<sup>3</sup> University of Göttingen Medical Centre, Germany; Private University of Applied Sciences, Germany

## Objective

This study was conducted to evaluate the (1) burden of disease, (2) satisfaction with diagnostic and treatment and (3) interventional needs in episodic and chronic cluster headache (eCH, cCH) as well as the (4) burden on the relatives of sufferers. The following interim **analysis focuses on the data of the relatives**.

## Methods

The Data were obtained systematically with an **online survey** in January and February 2023 among cluster headache patients and relatives. Diagnoses were made by treating physicians and rechecked by asking the ICH-3 criteria<sup>1</sup>. The survey included the CHS (Cluster Headache Scales)<sup>2</sup> to assess psychosocial factors in patients and the DASS (Depression, Anxiety, and Stress Scale)<sup>3</sup> to assess psychological burden in patients and relatives.

## Results

Out of 869 participating patients, **complete data sets from 640 patients were included** (354 eCH; 287 cCH; male (m): 373, female (f) 265, age 18-86 years). **For relatives, 147 complete data sets could be included** (m: 42, f: 104, age 18-79 years) out of 232. The relatives were mostly partners or family members (partners 72,8%, parents 10,2%, children 6,1%, siblings 2,0%, near friends 5,4%, colleagues 0,7% and others or unknown 2,7%) and in contact for a mean duration of 20.8 years ( $SD=13,7$ ). 80% of the relatives live together with the patients in one household.

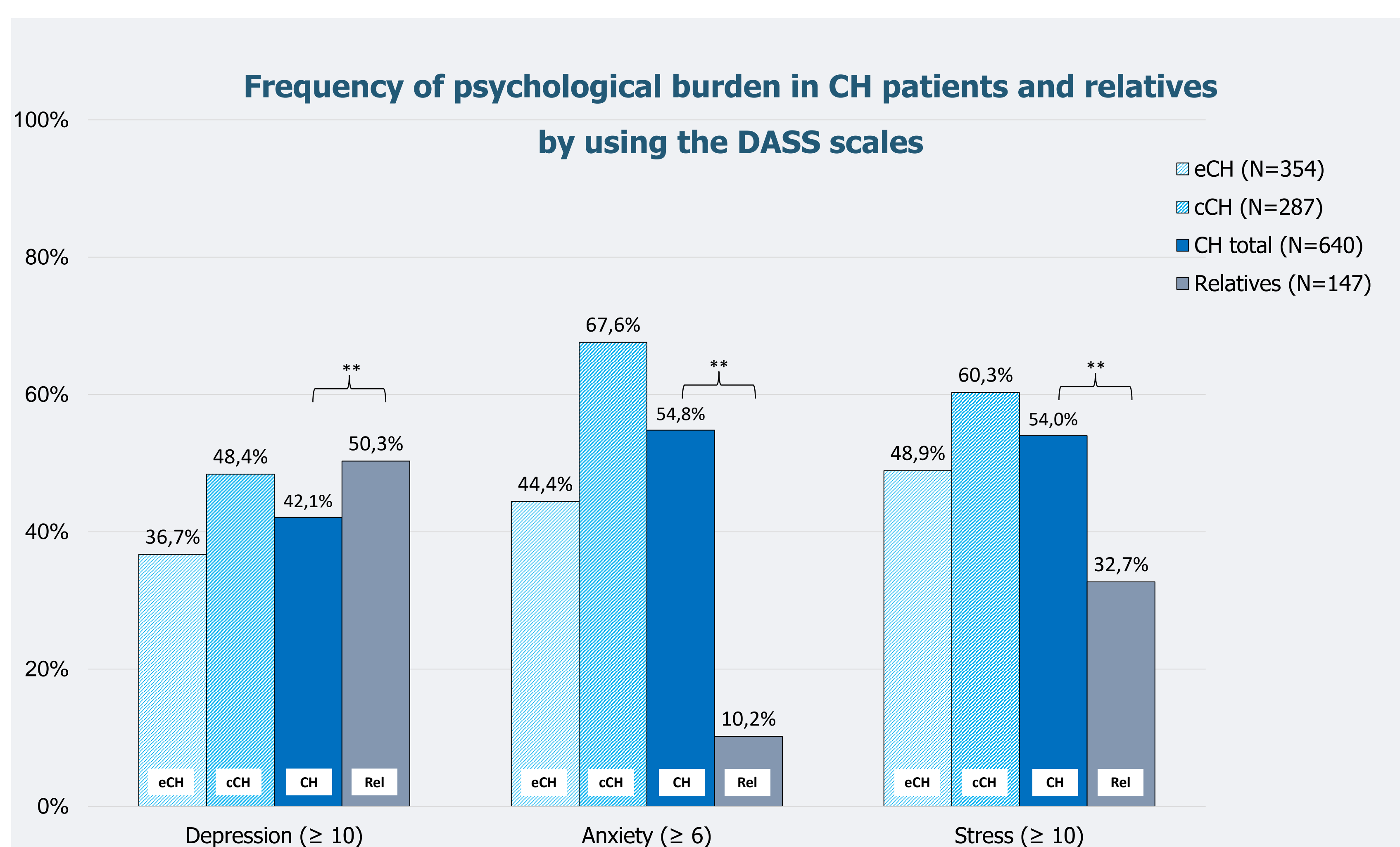
### Population

### Relationship

The **relationship** with the patient was found to be burdened by 68.7% of the relatives due to the CH. 90.5% felt a feeling of helplessness when present during a cluster headache attacks. In 31.3% of cases, the relatives perceived the patients to be aggressive during attacks. 87.1% of relatives reported that the disease was associated with psychological burden in patients. 85% were afraid of the further course of the disease, which was comparable to the patients (80.9%;  $p > 0.05$ ).

### Psychological Burden

Regarding **the psychological burden** a score  $\geq 10$  on the DASS depression scale was shown by 42.1% of patients and 50.3% of relatives, a score  $\geq 6$  on the DASS anxiety scale was shown by 54.8% of patients and 10.2% of relatives, a score  $\geq 10$  on the DASS stress scale was shown by 54.0% of patients and 32.7% of relatives. Patients had higher mean scores for anxiety (7.0 (5.1) vs. 3.2 (4.0),  $p < 0.01$ ,  $d = 0.77$ ) and stress (10.6 (6.1) vs. 7.1 (5.6),  $p < 0.01$ ,  $d = 0.59$ ) compared to relatives; for depression, relatives' mean scores were higher than patients' (11.3 (4.9) vs. 8.4 (6.7),  $p < 0.01$ ,  $d = 0.49$ ).

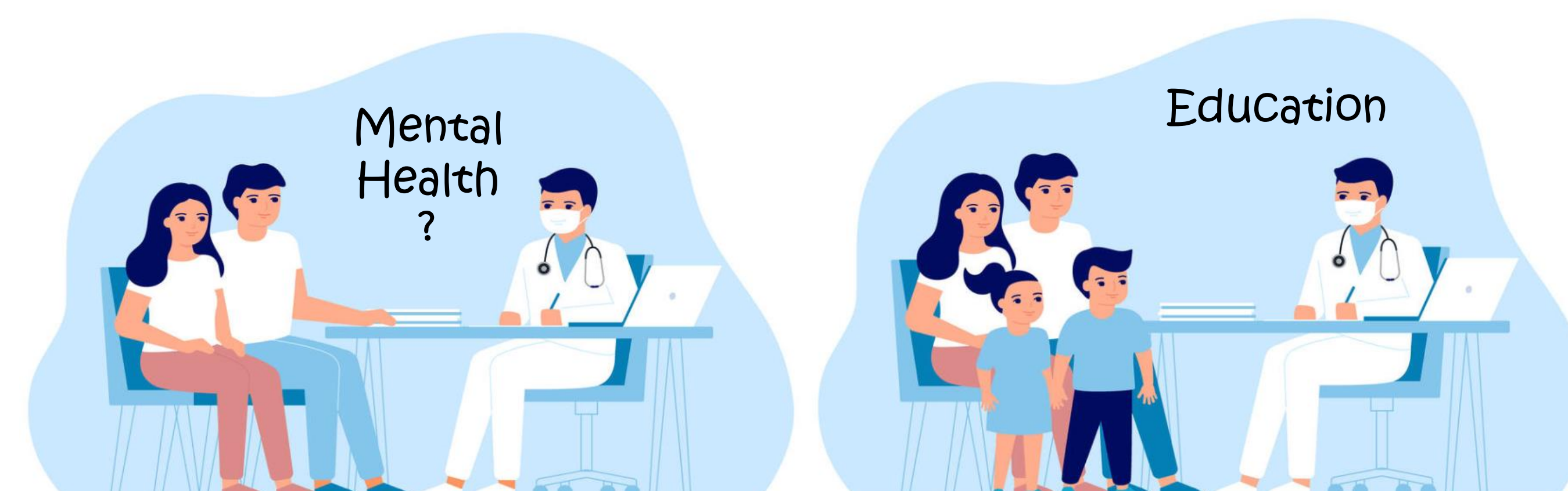


## Conclusion

This is the first study obtaining data on the psychological burden of CH patients and relatives in Germany. Using screening questionnaires, **a high level of psychological burden was found in both groups**. Data-based indications emerged that CH can severely strain the patient-family relationship. During attacks, (auto-)aggressive behavior of patients and a feeling of helplessness among relatives seem to be important characteristics.



**Professionals should pay attention to the psychological burden of the patients as well as their relatives and consider the psychological status in the therapy. It might be helpful to provide education for all involved.**



Presented at IHC

International Headache Congress 2023

14-17 Sept. in Seoul, Korea

**References** 1. The International Classification of Headache Disorders 3rd edition. Cephalalgia 2018;38:1-211 2. Klan et al. Determination of psychosocial factors in cluster headache - construction and psychometric properties of the Cluster Headache Scales (CHS). Cephalalgia 2020;40:1240-1249H 3. Lovibond PF, Lovibond SH. The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. Behaviour research and therapy 1995;33:335-343. 4. Nilges P, Essau C. Die Depressions-Angst-Stress-Skalen. Schmerz 2015;29:649-57

**Conflicts of Interest** C.G. has received honoraria for consulting and lectures within the past three years from Allergan Pharma, Lilly, Novartis Pharma, Hormosan Pharma, Grünenthal, Sanofi-Aventis, Chordate, Lundbeck Perfood, and TEVA. He is honorary secretary of the German Migraine and Headache Society. He does not hold any stocks of pharmaceutical Companies. M. S. has received compensation for travel expenses and registrations fees for several congresses from TEVA. J. F. has no conflict of interest