

Objective

Cluster headache (CH) is a primary headache disorder characterized by recurrent unilateral attacks of severe headaches. The disorder is associated with several psychological factors such as emotional and functional disability, psychological strain, and different ways of coping. **Aim:** To develop a self-report questionnaire that measures a broad range of relevant psychological aspects of CH – the Cluster Headache Scales (CHS).

Methods

The **CHS** were constructed based on the CH literature as well as semi-structured interviews with selected patients and practitioners. It consists of three parts.

- I. Socio-demographic data
- II. Disorder characteristics (e.g. type, duration, current disorder activity)
- III. Psychological aspects (95 Items; assumed core areas: strain, disability, and coping)

Procedure: A cross-sectional online survey was conducted via the German Federal association of the CH self-help groups. The survey included the CHS and other questionnaires (CCHS¹, DASS², IBK³, FKMS-K⁴, ESS⁵).

Sample: N = 302 CH sufferers (ICHD-3); 64.6 % male; age: M = 48.90, SD = 11.50; CH in years: M = 17.14, SD = 11.18; Episodic CH 51.2 %, Chronic CH 48.8 %; 52.3% reported to be in a bout or to have currently recurring headache attacks.

Results

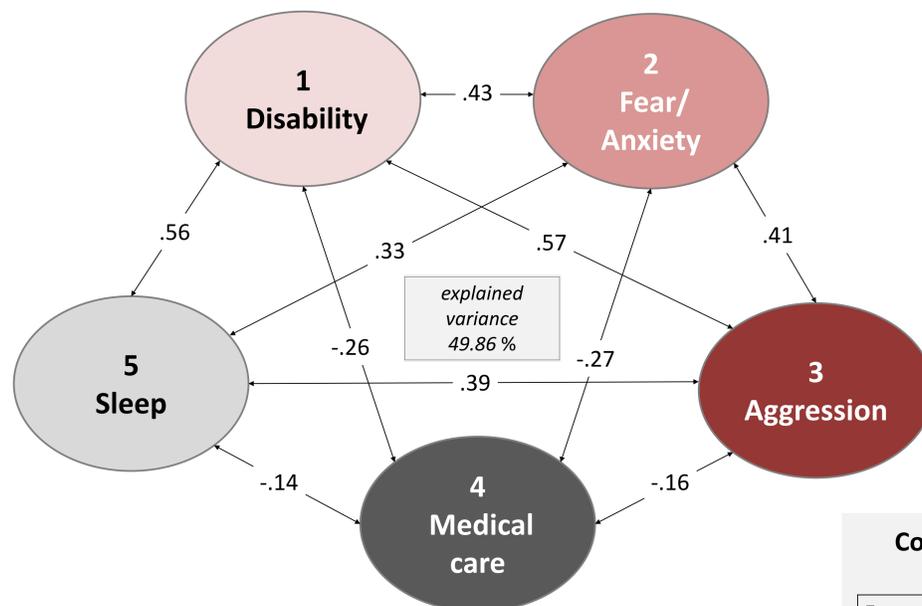
Cronbach's alpha

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| Scale 1 | .90 |
| Scale 2 | .91 |
| Scale 3 | .83 |
| Scale 4 | .83 |
| Scale 5 | .81 |

Convergent Validity – Scales CHS Part III

| Disability | Fear/Anxiety | Aggression | Medical care | Sleep |
|--|---|--|-------------------------|-------------------------|
| IBK-E: $r = .67, p < .01$ IBK-F: $r = .79, p < .01$ | IBK-E: $r = .56, p < .01$ DASS: $r = .45, .37, .42, p < .01$ | DASS: $r = .53, .45, .57, p < .01$ IBK-E: $r = .66, p < .01$ IBK-F: $r = .52, p < .01$ | FKMS-K: $r = .09, n.s.$ | ESS: $r = .21, p < .01$ |

Exploratory factor analysis (CHS Part III) yielded 5 subscales (final Version with 29 items):



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| 01. The CH disorder is determining my life. | $r_{it} = .66$ |
| 02. I feel limited in daily life. | $r_{it} = .64$ |
| 03. The CH disorder determines my daily routine. | $r_{it} = .70$ |
| 04. I am lonely because of my CH disorder. | $r_{it} = .66$ |
| 05. I withdraw socially because of my CH disorder. | $r_{it} = .68$ |
| 06. I suffer from the limitations caused by my CH disorder. | $r_{it} = .73$ |
| 07. I am limited in my scope of action due to my CH disorder. | $r_{it} = .61$ |
| 08. My vacation planning is affected by the disorder. | $r_{it} = .41$ |
| 09. My family life is impaired. | $r_{it} = .62$ |
| 10. My social contacts have become less due to my disorder. | $r_{it} = .69$ |
| 11. My social environment suffers from my illness. | $r_{it} = .58$ |

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| 1. I am afraid that the disorder could get worse. | $r_{it} = .73$ |
| 2. I am worried that the disorder could get worse. | $r_{it} = .75$ |
| 3. I am afraid of an CH attack. | $r_{it} = .81$ |
| 4. I am worried that an attack might occur. | $r_{it} = .78$ |
| 5. I panic when I think about the next attack. | $r_{it} = .73$ |
| 6. I am worried about the next attack. | $r_{it} = .77$ |

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| 1. I have sleep disturbances. | $r_{it} = .73$ |
| 2. My sleep-wake cycle is impaired. | $r_{it} = .77$ |
| 3. I often get tired during the day. | $r_{it} = .52$ |

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| 1. I receive a good medical treatment. | $r_{it} = .73$ |
| 2. I am satisfied with my medical treatment. | $r_{it} = .79$ |
| 3. My medical treatment is effective. | $r_{it} = .70$ |
| 4. My acute medication is effective. | $r_{it} = .42$ |

Convergent Validity: current disorder activity (section of CHS Part II)

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| Frequency of CH (attacks/day) | CHSS (total score) $r = .26, p < .01$ |
| Mean duration of CH attack | CHSS (total score) $r = .33, p < .001$ |
| Mean intensity of CH attack | CHSS (total score) $r = .03, n.s.$ |

Conclusion

Exploratory factor analysis of CHS part (III) yielded 5 subscales, each with a good to excellent Cronbach's alpha. With regard to the subscales, we reduced the CHS part III to 29 items. The correlations between subscales of the CHS and scales of other relevant measures were mostly moderate or strong. Our results support the use of the CHS as a reliable and valid self-report questionnaire for assessing psychological factors associated with CH disorder. The CHS also represents a promising tool for treatment planning and treatment outcome research. Future research should aim at determining the test-retest reliability and validating the proposed structure using confirmatory factor analyses.

References:

1 Steinberg, A., Fourier, C., Ran, C., Waldenlind, E., Sjöstrand, C., Belin, A. C. (2018). Cluster headache - clinical pattern and a new severity scale in a Swedish cohort. *Cephalalgia* 38 (7), S. 1286–1295. 2 Nilges, P., & Essau, C. (2015). Die Depressions-Angst-Stress-Skalen: Der DASS – ein Screeningverfahren nicht nur für Schmerzpatienten (Depression, anxiety and stress scales: DASS – A screening procedure not only for pain patients). *Schmerz (Berlin, Germany)*, 29(6), 649–657. 3 Bauer, B., Evers, S., Gralow, I., & Husstedt, I.-W. (1999). Psychosoziale Beeinträchtigung durch chronische Kopfschmerzen. *Der Nervenarzt*, 70(6), 522–529. German Version of the HDI: Jacobson, G. P., Ramadan, N. M., Aggarwal, S. K., & Newman, C. W. (1994). The Henry Ford hospital headache disability inventory (HDI). *Neurology*, 44(5), 837–837. 4 Graef, J. E., Rief, W., French, D. J., Nilges, P., & Nestoriuc, Y. (2015). German Language Adaptation of the Headache Management Self-Efficacy Scale (HMSE-G) and Development of a New Short Form (HMSE-G-SF). *Headache*, 55(7), 958–972. 5 Sauter, C., Popp, R., Danker-Hopfe, H., Büttner, A., Wilhelm, B., Binder, R., ... Weeß, H.-G. (2007). Normative values of the German Epworth Sleepiness Scale. *Somnologie - Schlaforschung Und Schlafmedizin*, 11(4), 272–278.

Conflicts of Interest:

C. Gaul has received honoraria for consulting and lectures within the past three years from Allergan Pharma, Ratiopharm, Boehringer Ingelheim Pharma, Lilly Germany, Novartis Pharma, Desitin Arzneimittel, Cerbotec, Bayer Vital, Hormosan Pharma, electroCore, Grunenthal, Reckitt Benckiser, and TEVA. E. Liesering-Latta has received honoraria for lectures within the past two years from Reckitt Benckiser, Allergan Pharma, Lilly Germany. A. Vales, M. Withthöft, and T. Klan have no conflicts of interest.