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Greater occipital nerve modulation and clinical aspects of cluster headache

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CHAPTER 6

Translating the Cluster Headache Quality of Life Questionnaire (CHQ) from English to Dutch with the TRAPD method

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ABSTRACT

Objective: Cluster headache is associated with a decreased quality of life (QoL). The increased focus on patient-reported outcome measures (PROMS) has led to the creation of a tailored Cluster Headache Quality of Life scale (CHQ). Our objective was to create and authenticate a Dutch version of the CHQ (CHQ-D).

Methods: The TRAPD model (Translation, Review, Adjudication, Pretesting, Documentation) was used to translate the CHQ from English to Dutch and ensure cross-cultural adaption. Pre-testing was performed in n = 31 participants, and validity was in a new sample of n = 40 participants who completed the CHQ twice at a 2-day interval. Intraclass correlation coefficient (ICC) and Cronbach's alpha were used to assess the validity and reproducibility of the CHQ-D.

Results: To produce the CHQ-D, we made five modifications based on pretesting. Participants finished the questionnaire in a median time of 10 min (IQR:10.0, 17.5) and 90% within 20 min. The majority of participants (74.2%) did not find it burdensome at all. The reliability of the CHQ-D was excellent (Cronbach's alpha: 0.94; ICC: 0.94).

Conclusion: The CHQ-D is a valid and practical instrument for QoL in individuals with cluster headache. We aim to use CHQ-D as PROM in clinical research in the Netherlands to enforce international collaborations and comparisons of studies.

Keywords: Cluster Headache Quality of Life Questionnaire; Cluster headache; Patient-reported outcome measurement; Quality of life; Trigeminal autonomic cephalalgia.

INTRODUCTION

Cluster headache is associated with a decreased quality of life (QoL).[1] In recent years, there has been greater emphasis on patient-reported outcome measures (PROMS). In line with this development, the newly revised clinical trial guidelines for cluster headache advised to incorporate these measures as clinical trial end point.[2] Despite the specific characteristics of cluster headache, no validated QoL questionnaire for cluster headache was available until 2016, when the Cluster Headache Quality of Life scale (CHQ) was developed.[3]

The CHQ is a short, easy to use questionnaire regarding patients' day-to-day lives. The scale was developed in consultation with cluster headache patients and clinicians. The CHQ consists of 30 questions that includes four domains related to QoL: "restriction of activities of daily living", "impact on mood and interpersonal relationships", "pain and anxiety" and "lack of vitality".[3] The English CHQ questionnaire is validated and reliable.[3]

Unfortunately, the CHQ is not available in Dutch, leading to the usage of the, less ideal, generic QoL questionnaires such as the Short-Form-36. [4], LICON] The use of a foreign questionnaire is prone to bias with linguistic nuances and cultural aspects that might lead to an incorrect interpretation of the outcome. This study therefore aimed to develop and validate a Dutch translation of the CHQ.[5] To ensure correct interpretation and accurate results, adequate translation methods need to be used.

The translation and validation of the Cluster Headache Quality of Life scale from English to Dutch using the TRAPD (Translation, Review, Adjudication, Pretesting, and Documentation) team translation model will be reported here.

MATERIAL AND METHOD

Study Design

A multi-step and team-based translation process in conformity with the TRAPD model (Translation, Review, Adjudication, Pretesting and Documentation; Figure 1) was used to translate the CHQ from English to Dutch and ensure cross-cultural adaption.[5] After the definite Dutch translation was achieved, the scale was validated in the second part of this research. Written informed consent was obtained from all participants and the study protocol was approved by the ethical committee of the LUMC (METC-LDD; Reference number 22-3008). Data were collected between June 2022 and October 2022.

Cluster Headache Quality of Life scale (CHQ)

The original CHQ was provided by the designers of the questionnaire (Abu Bakar et al.[3], supplementary file 2). The CHQ scale consists of 28 items, in which the frequency of certain complaints and feelings are scored. Each item is answered using a 5-point Likert scale ('never' (=0), 'occasionally' (=1), 'sometimes' (=2), 'often' (=3), 'always' (=4)). The minimum obtainable score of the total questionnaire is 0, the maximum is 112. Higher scores indicate a poorer health related QoL. In addition to the total score, four sub scores can be calculated corresponding to four subdomains: (i) "restriction of activities of daily living" (item 1-9), (ii) "impact on mood and interpersonal relationships" (10-21), (iii) "pain and anxiety" (22 & 23) and (iv) "lack of vitality" (24-28). Lastly, a 100 mm visual analogue scale, ranging from "not at all satisfied" to "very satisfied", is included at the bottom of the original questionnaire. This scale is scored according to distance from the left side of the scale to the drawn line of the patient. Higher scores (i.e. more distance from the left side) indicate better overall health-related QoL. This score is not included in the total CHQ score.

Participants

Participants were selected from the Leiden University Cluster headache neuro Analysis (LUCA) cohort.[6] The LUCA cohort is a validated, web-based cohort with a screening questionnaire for cluster headache based on the ICHD-3 criteria.[6] Patients were invited to participate either in the translation process (N=31) or in the validation process (N=40). Inclusion criteria were: being a native-Dutch speaker, being 18 years or older and having a diagnosis of episodic or chronic cluster headache or CCH as defined by the ICHD-3 criteria.[7] Participants that were attack free for > 3 years were excluded. Sociodemographic about participants including age, sex, level of school education and disease-specific information (type of cluster headache, attack frequency) were collected.

Translation process

The translation was performed with the use of the TRAPD method. This method was originally developed by Janet Harkness and is the preferred method for the translation and adaption of questionnaires according to the Cross-Cultural Survey Guidelines.[5, 8] This method consists of 5 different steps: (i) Translation, (ii) Review, (iii) Adjudication, (iv) Pretest, (v) Documentation (figure 1). All steps of the translation process (different translated versions, discussion notes, etc.) were carefully documented.

i) Two translators (RH and DF) both proficient in English and native Dutch speakers with experience in the cluster headache field independently translated the questionnaire from English to Dutch.

ii) The two preliminary translations were reviewed by the translators and an independent reviewer (WN). For each question, the best wording was discussed to achieve a single pre-final translation.

iii) The pre-final Dutch translation was compared and considered equal to the original (English) version by the adjudicator (RB). This pre-final translation was used for the *Pretest*.

iv) The pre-final questionnaire was pretested in the 'pretest cohort', consisting of 31 people with cluster headache. During the pretest, participants were asked to complete the questionnaire online. Furthermore, participants were offered the possibility to leave remarks about clarity and wording after each question. Lastly, survey burden was evaluated using a 6-point Likert scale (1 = 'not burdensome at all' - 6 ='very burdensome'). An interview by phone was conducted in all participants when they had completed the questionnaire. Their interpretation of each of the questions and any perceived ambiguities were evaluated. Finally, participants were asked if they had any additional comments or remarks.

All feedback that was collected during the pretest was reviewed by the two individual translators and the reviewer by repeating the first three steps of the TRAPD model until an agreement was reached on the revised final version of the translation. Hereafter the final translated Dutch version of the CHQ will be called the CHQ-D ("Cluster Headache Quality of Life scale – Dutch version ").

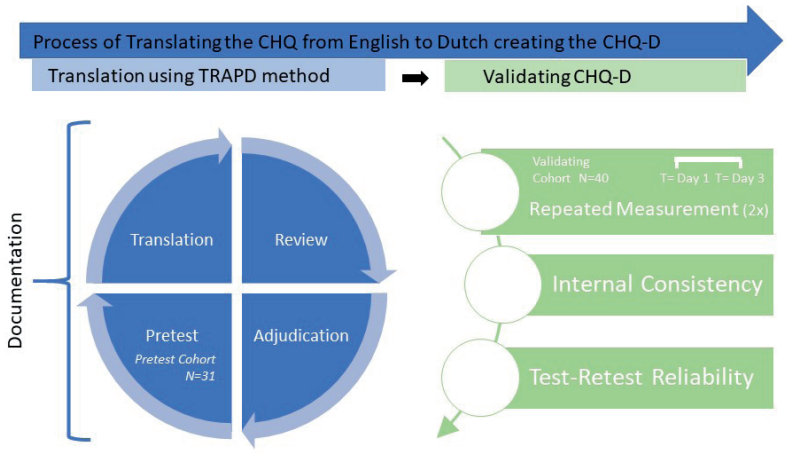


Figure 1 – Overview of the Process of Translating and Validating the CHQ, resulting in the CHQ-D.
Left side: The CHQ was translated using the TRAPD method (5 steps: *Translation, Review, Adjudication, Pretest, Documentation*) including preliminary testing of the questionnaire in a pretest cohort of 31 participants with cluster headache.
Right side: The CHQ-D was validated using a validation cohort of 40 participants with cluster headache who completed the questionnaire twice with a two day interval after with the internal consistency and test-retest reliability was calculated.
Legend: CHQ: Cluster Headache Quality of Life Questionnaire, CHQ-D: Cluster Headache Quality of Life scale – Dutch version

Validation of the CHQ-D

The reliability and validity of the CHQ-D was tested in a new sample of 40 participants (Figure 1), who were instructed to complete the questionnaire twice with a two day interval. Due to the inherent fluctuations in disease activity and possible confounding factors, the retest interval should be as short as possible, while avoiding recall. A two-day interval was shown to be equivalent to a two week interval.[9] Participants were asked to complete the questionnaire both times in a comparable setting (e.g. at home in the evening).

Statistical Analysis

Descriptive data are presented as number (percentage) or median (interquartile range)/mean (SD), depending on distribution of data. For group comparisons, Chi-square tests, Fisher's exact tests, Student's t-tests or Mann-Whitney tests were performed when appropriate. A chi-square test was used to assess if level of education was associated with the amount of remarks on the questionnaire during the preliminary test compared.

Internal consistency was calculated with Cronbach's Alpha for the first CHQ-D measurement of the participants of the Validation Cohort. Internal consistency as determined by Cronbach's Alpha is deemed acceptable when greater than 0.7 and excellent when greater than 0.8. The

floor effect was quantified as the percentage of patients who achieved the minimal score and the ceiling effect as the percentage achieving the maximum score.

To estimate test-retest reliability, Intraclass Correlation Coefficient (ICC) was calculated. The ICC estimates and their 95% confident intervals were calculated for the total CHQ score and each item of the CHQ based on a single-rating, absolute-agreement, 2-way mixed-effects model.[10] ICC values of less than 0.5 indicate poor reliability, values between 0.5 and 0.75 moderate reliability, values between 0.75 and 0.9 good reliability, and values greater than 0.90 excellent reliability.[10]

To visualize the reproducibility and the degree of similarity between both completed questionnaires, a Bland Altman plot was created.[11] The 95% limits of agreement (LOA) is calculated as the mean difference between the two measurements of the total CHQ-D score ± 1.96 standard deviations.

All statistical analyses were performed with RStudio version 4. Two-tailed p values less than 0.05 were considered statistically significant.

RESULTS

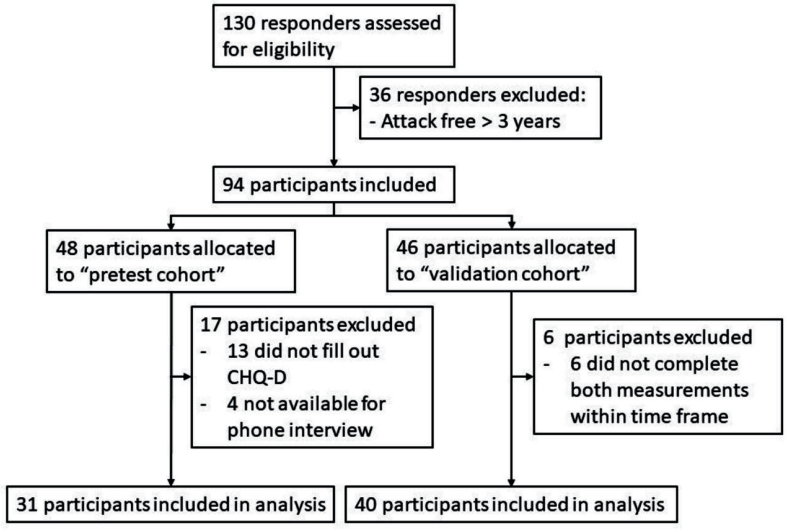
Translation

The questionnaire was divided into 41 items (title, 2 parts introduction, 31 questions, 7 options of choice) which were translated by the two independent translators. In 31.7% (N=13) of the items there was complete similarity between both preliminary translations, in 41.5% (N=17) there was partial similarity and in 26.8% (N=11) there was minimal or no similarity. The minimal differences mostly consisted of a different sentence structure and in case of no similarity it was due to a different choice of words. After comparing and discussing the differences, consensus was achieved in all cases resulting in a preliminary version of the translated questionnaire. After comparing this preliminary version of translation with the original CHQ questionnaire, the adjudicator had content-related comments on 3 items. In consultation with translators, reviewer and adjudicator, 1 adjustment was made before completing the pre-final version of the questionnaire.

Participants

Nine-hundred cluster headache patients from the LUCA cohort were invited for participation. One-hundred-thirty of the 900 (14%) eligible cluster headache patients from the LUCA cohort were interested, of whom thirty-six people (27.7%) were excluded because they were cluster headache attack free for more than 3 years.

Figure 2 – Flow chart



Legend: CHQ-D: Cluster Headache Quality of Life scale – Dutch version the Dutch translation of the CHQ questionnaire

The pre-final version of the translated questionnaire was sent to 48 participants for preliminary testing, of whom 31 (64.4%) completed the questionnaire and had an interview by phone. The revised and final CHQ-D (Supplemental 1) was sent to 46 participants for validation, of which 40 (87.0%) completed both measurements of the questionnaire. The demographic and clinical characteristics did not differ between the test cohort and the validation cohort (Table 1).

Table 1. Demographics of cluster headache population of the Test and Validation phase.

	Test cohort (n=31)	Validation cohort (n=40)	*p*-value
Demographic characteristics			
Male, N (%)	17 (54.8)	25 (62.5)	0.683
Age (years), median [IQR]	59.0 [53.0, 63.0]	54.5[41.8, 63.3]	0.167
Education, N (%):			0.842
– Primary education	0 (0.0)	1 (2.5)	
– Secondary education	4 (12.9)	5 (12.5)	
– Secondary vocational education	9 (29.0)	14 (35.0)	
– Higher professional education	13 (41.9)	13 (32.5)	
– University education	5 (16.1)	7 (17.5)	
Episodic CH, N (%)	17 (54.8)	19 (47.5)	0.708
In-episode, N (%)	2 (11.8)	2 (12.5)	
No CH attacks last month, N [IQR]	17.5 [2.5, 28.5]	15.0 [5.0,57.5]	0.502

Legend: IQR: Interquartile Range, CH: Cluster Headache

Preliminary testing

Complete results of the preliminary tests are shown in Table 2. The median time for participants to complete the questionnaire was 10 minutes (IQR: 10.0, 17.5). Most participants experienced completing the questionnaire as 'not burdensome at all' (74.2%) and none experienced it as "very burdensome". Higher survey burden scores were mostly due to the fact that the questionnaire was found confronting regarding the severity of their condition.

After completion of the questionnaire and evaluation by phone, 9 participants (29%) had minor remarks about the clarity or wording of the questionnaire. No significant correlation was found between level of education level and having comments (p=0.95). In total, there were 24 remarks divided over 10 items of the questionnaire. Most of the comments focused on the common part of the question *(in English "Due to cluster headache, in the past month or last episode, how often have you …")*, question 1, 2 and 3, as depicted in Table 3.

After review of all comments by the translators and the reviewer, five adjustments were made to the CHQ-D. The common part of the question was shortened for clarification (to *'Vanwege uw clusterhoofdpijn, hoe vaak heeft u/bent u'*). The deleted part was added to the

introduction. In order to make question 1 and 2 more fluent, the article was removed. An article was added in question 3 (‘*het werk’)*. The final question (‘*Self-reported satisfaction with life’*), was adjusted to be more easily understood. The outcome of this question was changed from a 100 mm visual analogue scale to a numeric 10-point Likert Scale, leading to a more comprehensible question and a better fit for the digital format of the questionnaire *(‘Hoe tevreden bent u met uw leven op een schaal van 1-10?’)*. The remaining suggestions were not incorporated in the final translation. They would either change the question in a way that did not match the original question, or were aimed at the overall content and not the linguistics of the questionnaire (e.g. missing some elements of QoL in the questionnaire).

Table 2. Results of the evaluation of the pre-final version the translation of the CHQ in the Test Cohort

	Test cohort (N=31)
Pre-final CHQ-D results	
Duration completion questionnaire (min), median [IQR])	10.0 [10.0, 17.5]
Burdening completing questionnaire*, N (%)	
1	23 (74.2)
2	5 (16.1)
3	2 (6.5)
4	1 (3.2)
5	0
6	0
Total score CHQ-D, mean (±SD)	63.0 (16.1)
Subscores, mean (±SD)	
Restrictions of activities of daily living	24.0 (6.9)
Impact on mood and interpersonal relationships	20.3 (7.7)
Pain and anxiety	5.4 (1.7)
Lack of vitality	13.32 (3.60)
Self-reported satisfaction with life, median [IQR])	7.0 [6.0, 8.0]

Legend: CHQ-D: Cluster Headache Quality of Life scale – Dutch version the Dutch translation of the CHQ questionnaire. IQR: Interquartile range, SD: Standard deviation
** This was scored using a 6-point Likert scale, where 1 was ‘not burdensome at all’ and 6 ‘very burdensome’

Table 3: Most commented items of the pre-final version of the translation of the CHQ after pretesting

Item	**Number of comments, N (% of all respondents)**
Preliminary Question: *‘Hoe vaak heeft u/bent u vanwege uw clusterhoofdpijn in de afgelopen maand of tijdens uw laatste episode’*	6 (19.4)
Question 1: *‘Het vermeden om de deur uit te gaan’*	4 (12.9)
Question 2: *‘Het vermeden om plannen te maken vanwege de onvoorspelbaarheid van clusterhoofdpijn’*	4 (12.9)
Question 3: *‘Zich niet in staat gevoeld om taken op werk te voltooien’*	3 (9.7)
Final Question: *‘Beoordeel op de onderstaande schaal uw algehele tevredenheid over uw leven met een markering op een bij u passend punt.’*	2 (6.5)

Validation

The mean time between completing both measurements was 2.08 days (SD±0.27). Three participants completed both measurements on day 1 and day 4 with an interval of 3 instead of the intended 2 days. The Cronbach's alpha was 0.94 for the first measurement of the CHQ-D-questionnaire (Table 5), which is well above the threshold of 0.8 and deemed excellent. Table 5 shows the Cronbach's Alpha for each of the four subcategories. In addition, the corrected item to total correlation is depicted for items in their respective subcategory.

The Bland-Altman plot (Figure 2) visualizes the difference of the total score of the CHQ-D-questionnaire between the two measurements, which was-2.28 with a 95% limit of agreement (LOA) between-9.17 and 13.72 (Table 4). All but two (5%) participants were within the LOA. No relationship between the total score of the questionnaire and the difference between two measurements was observed. No floor or ceiling effect was observed as none of the participants scored the minimum (0) or maximum (112) score (range 22 to 99).

The intraclass correlation coefficient (ICC) for the complete CHQ-D-questionnaire was 0.94 (95% CI 0.88 ; 0.97), which classified the test-retest reliability of the questionnaire as excellent (Table 6). All subscores had good reliability (ICC > 0.75). Each individual item had at least moderate reliability (ICC > 0.6), with more than half of the items having at least good reliability (ICC > 0.75) (Supplemental 3).

Table 4. Results final CHQ-D of the Validation Cohort

	Validation Cohort (N=40)		
CHQ-D results	Time 1	Time 2	Difference
Total score CKHV, mean (±SD)	54.1 (17.0)	51.8 (18.10)	-2.3 (5.8)
Subscores, mean (±SD)			
Restrictions of activities of daily living	21.3 (6.6)	19.9 (6.78)	-1.5 (3.1)
Impact on mood and interpersonal relationships	15.8 (8.6)	15.4 (9.11)	-0.4 (3.7)
Pain and anxiety	5.3 (1.6)	4.9 (1.42)	-0.4 (0.9)
Lack of vitality	11.6 (3.1)	11.6 (3.53)	-0.5 (2.0)
Self-reported satisfaction with life, median [IQR])	7.0 [6.0, 8.0]	7.0 [6.0, 8.0]	0.0 (0.0, 0.0)

Legend: CHQ-D: Cluster Headache Quality of Life scale – Dutch version. IQR: Interquartile range, SD: Standard deviation

Table 5. Chronbach's alpha for Total CHQ-D score and underlying subscales.

Scale	No Items	Chronbach's Alpha
Total score CKHV	28	0.94
Subscales		
Restrictions of activities of daily living	9	0.93
Impact on mood and interpersonal relationships	12	0.88
Pain and anxiety	2	0.61
Lack of vitality	5	0.75

Legend: CHQ-D: Cluster Headache Quality of Life scale – Dutch version. IQR: Interquartile range, SD: Standard deviation

Table 6. Intraclass Correlation Coëfficiënt

Item	Intraclass correlation coefficient	95% CI	
		Lower bound	Upper bound
Total score CHQ scale	0.938	0.877	0.968
Subscales			
Restriction of ADL	0.875	0.742	0.937
Impact on mood and interpersonal relationships	0.914	0.844	0.954
Pain and anxiety	0.799	0.627	0.893
Lack of vitality	0.820	0.685	0.901
Overall satisfaction with life	0.896	0.812	0.944

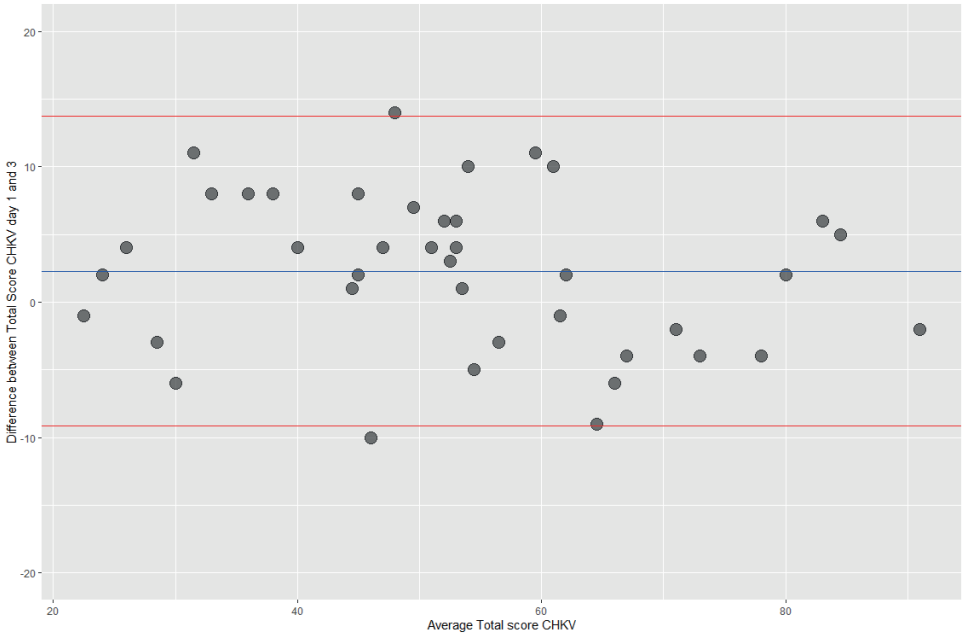


Figure 2 – Bland Altman plot of the Difference between the Total CHQ-D scores for both measurements of the CHQ-D (*Survey filled out on day 1 vs day 3*). The mean difference was-2.28 (blue line) and the 95% limits of agreement (LOA; red line) were 13.72 and-9.17. Differences between both measurements were, apart from two, within the LOA. No association between the total score of the questionnaire and the difference between two measurements was indicated.

DISCUSSION

This study demonstrates the translation and validation of the Cluster Headache Quality of Life scale from English to Dutch. The translation process with the TRAPD method included cross-cultural validation and resulted in the Dutch version of the CHQ, known as the CHQ-D: Cluster Headache Quality of Life scale – Dutch version: A patient-friendly QoL scale that is easy-to-use and quick to complete. The reproducibility and internal consistency are both good (CHQ-D sub-scores) to excellent (total CHQ-D score) and are consistent with the results of the validation of the original CHQ.[3] Due to the absence of floor and ceiling effects in our analyses, the CHQ-D is applicable to patients with a very low or a very high QoL as well.

To the best of our knowledge, this is the first translation of the CHQ and the first Dutch cluster headache specific QoL scale. The CHQ-D enables future studies to quantify different aspects of the QoL of the Dutch-speaking CH population. Greater emphasis on patient-reported outcome measures (PROMS) in clinical trials demonstrate the need for better and more specific measures of quality of life. Moreover, determinants of QoL could identify unmet needs of cluster headache patients and highlight areas where more (non)-pharmacological interventions are indicated.

The CHQ is able to detect differences in impairment of QoL between mild and severe CH.[3] This creates the possibility to incorporate this measure in longitudinal studies, correlating intra-patient variability of QoL to fluctuations in CH severity (i.e. attack frequency). More information should be gathered about factors that impact QoL (e.g. age/sex-differences, treatment effects incl. adverse events) of the Dutch CH population. Ultimately, increasing the QoL of CH patients.

One of the strengths of this study is the use of the TRAPD translation guideline, which has been followed strictly.[5] This resulted in a translation that is not only grammatically correct Dutch, but includes linguistic nuances and cross-cultural differences as well. The accuracy and quality of the translation process was highlighted by the fact that the pre-final version of the translation hardly needed any changes after the pre-tests. The results can be generalized to the entire Dutch-speaking cluster headache population, since participants were included from the well-validated nationwide web-based LUCA cohort and were from different parts of the Netherlands with different Dutch dialects.

The contribution of chronic (45-51%) cluster headache patients is higher than expected based on the known prevalence of the chronic type in the general CH population.[12] Since chronic cluster headache is correlated with a lower QoL,[13] the use of QoL scales such as the CHQ-D are especially important for chronic cluster headache patients. The relative overrepresentation

of chronic cluster headache in our study cohort therefore increases the practical validity of the CHQ-D. There might be an overestimation of the test-retest reliability due to the two day interval between both measurements of the CHQ-D. The two day interval between both measurements was intended to keep the disease activity and other possible confounding factors as stable as possible. Unfortunately, this relatively short interval could inadvertently have led to the recollection of answers from the first measurement. However, this possible overestimation is expected to be limited since a two-day interval is considered to be equivalent to a two week interval.[9]

In conclusion, the Dutch translation of the CHQ scale, the CHQ-D, is a valid, reliable, easy-to-use and practical instrument to assess cluster headache related disability and impairment on the quality of life, and is comparable to the original English version of the scale. The CHQ-D can be used in the clinical setting to monitor QoL as part of the regular patient care or as patient-reported outcome measure (PROM) in clinical trials in the Netherlands.

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SUPPLEMENTAL 1. FINAL TRANSLATION

CLUSTERHOOFDPIJN KWALITEIT VAN LEVEN VRAGENLIJST (CHQ-D)

Hoe vaak heeft u in de afgelopen maand een clusterhoofdpijn aanval gehad? _____

Beantwoord de onderstaande vragen om aan te geven hoe vaak clusterhoofdpijn verschillende aspecten van uw leven heeft beïnvloed.

De vragen gaan over de afgelopen maand, tenzij u geen aanvallen heeft gehad. Dan gaat het over uw meest recente clusterhoofdpijn episode.

Kruis bij elke vraag slechts één vakje aan. Laat geen vragen onbeantwoord.

Vanwege uw clusterhoofdpijn, hoe vaak heeft u/bent u:	Nooit	Zelden	Soms	Vaak	Altijd
1. Vermeden om de deur uit te gaan					
2. Vermeden om plannen te maken vanwege de onvoorspelbaarheid van clusterhoofdpijn (bijv. vakanties)					
3. Zich niet in staat gevoeld om taken op het werk te voltooien					
4. Moeite gehad om activiteiten in uw vrije tijd te ondernemen (bijv. naar de bioscoop of het theater gaan, etc.)					
5. Drukke en rumoerige plekken vermeden (bijv. openbaar vervoer, kroegen, etc.)					
6. Het gevoel gehad dat de ernst van uw clusterhoofdpijn uw dagelijks leven heeft beïnvloed					
7. Minder betrokken geweest bij familiegelegenheden (bijv. omgang met kinderen, het plannen van vakanties, etc.)					
8. Niet in staat geweest om tijd te besteden aan sociale activiteiten/om te gaan met familie en vrienden					
9. Niet in staat geweest om dagelijkse doelen te behalen en dagelijkse bezigheden en taken uit te voeren					
10. Zich minder gerespecteerd gevoeld door anderen					
11. Problemen gehad met hechte persoonlijke relaties					
12. Het gevoel gehad tot last te zijn voor familie en vrienden					
13. Een zelfbewust of ongemakkelijk gevoel gehad over uw uiterlijk na een clusterhoofdpijnaanval (bijv. door gezwollen/rode ogen of een bezweet gezicht, etc.)					
14. Het gevoel gehad dat anderen uw clusterhoofdpijn niet serieus namen					
15. Zich agressief gevoeld					
16. Een slecht gevoel gehad over uzelf, minder zelfvertrouwen ervaren of zich onbelangrijk gevoeld					

Vanwege uw clusterhoofdpijn, hoe vaak heeft u/bent u:	Nooit	Zelden	Soms	Vaak	Altijd
17. Zichzelf iets willen aandoen of suïcidale gedachten gehad					
18. Prikkelbaar, ongeduldig of minder verdraagzaam geweest					
19. Vergeetachtig geweest (bijv. afspraken gemist)					
20. Niet in staat geweest om voor uw uiterlijk te zorgen (bijv. douchen, make-up opdoen, omkleden, etc.)					
21. Zich geïsoleerd, eenzaam of kwetsbaar gevoeld					
22. Het gevoel gehad dat uw pijn ondraaglijk was als deze niet behandeld zou worden					
23. Gevreesd dat uw hoofdpijn niet over zou gaan					
24. Een gebrek aan energie gehad en zich constant moe gevoeld					
25. Zich slaperig, uitgeput of niet goed in staat gevoeld om te concentreren door nachtelijke aanvallen van clusterhoofdpijn					
26. Concentratieproblemen gehad (bijv. bij krant lezen of tv kijken, etc.)					
27. Zich niet in staat gevoeld helder na te denken					
28. Zich gespannen of angstig gevoeld					

Hoe tevreden bent u met uw leven op een schaal van 1-10? _____

(1 = helemaal niet tevreden, 10 = zeer tevreden)

Supplemental 2. English original Cluster headache quality of life questionnaire (CHQ)

CLUSTER HEADACHE QUALITY OF LIFE QUESTIONNAIRE (CHQ)

How many times have you experienced a cluster headache attack during the last month?

Please complete the following items to indicate how often cluster headache has affected various aspects of your life DURING THE LAST MONTH or DURING YOUR MOST RECENT CLUSTER HEADACHE EPISODE

Please tick only one box for each item. Do not leave any item blank.

Due to cluster headache, in the past month or last episode, how often have you:	**Never**	**Occasionally**	**Sometimes**	**Often**	**Always**
1. Avoided leaving the house					
2. Avoided making plans due to unpredictability of cluster headache e.g. holidays					
3. Felt unable to complete duties at work					
4. Had difficulty in getting involved in leisure activities e.g. cinema, theatre, etc?					
5. Avoided crowded and noisy places e.g. public transport, pubs, etc					
6. Felt that the severity of cluster headache affected your daily activities					
7. Been less involved in family affairs e.g. interaction with children, planning holidays					
8. Been unable to socialise/spend time with friends and family					
9. Been unable to achieve your daily goals and carry out routines and chores					
10. Felt less respected by others					
11. Had problems with close personal relationship					
12. Felt you were a burden on family and friends					
13. Felt self-conscious and uncomfortable about your appearance after a cluster headache attack (eg swelling/redness of eyes and facial sweating, etc)					
14. Felt that others are dismissive of your cluster headaches					
15. Felt aggressive					
16. Felt bad about yourself, lost self-confidence or felt worthless					
17. Felt like harming yourself or suicidal					
18. Been irritable, impatient or less tolerant					
19. Been forgetful e.g. missed appointments					

Due to cluster headache, in the past month or last episode, how often have you:	Never	Occasionally	Sometimes	Often	Always
20. Been unable to take care of your appearance (eg take a bath, put make- up on, change clothes, etc)					
21. Felt isolated, lonely or vulnerable					
22. Found your pain is unbearable if untreated					
23. Dreaded that the headache would not go away					
24. Felt lacking in energy and constantly tired					
25. Felt sleepy, worn out or less able to concentrate due to nocturnal attacks of cluster headache					
26. Had problems concentrating e.g. reading paper, watching TV, etc					
27. Been unable to think clearly					
28. Felt tense or anxious					

Please rate your overall satisfaction with your life by placing a vertical line on the scale below at an appropriate point

| |

Not at all satisfied Very satisfied

Supplemental 3

Table. Intraclass Correlation Coefficient for all individual questions

Item	Intraclass correlation coefficient	95% CI		F Test With True Value 0			
		Lower bound	Upper bound	Value	*df*1	*df2*	Sig
Restriction of ADL							
1. Avoided leaving the house	0.755	0.581	0.862	6.99	39	39	8.4e-09
2. Avoided making plans due to unpredictability of cluster headache e.g. holidays	0.83	0.703	0.906	10.7	39	39.1	6.89e-12
3. Felt unable to complete duties at work	0.618	0.374	0.78	4.61	39	32.5	1.18e-05
4. Had difficulty in getting involved in leisure activities e.g. cinema, theatre, etc	0.709	0.513	0.835	5.78	39	39.3	1.21e-07
5. Avoided crowded and noisy places e.g. public transport, pubs, etc	0.744	0.566	0.856	7.07	39	38.4	8.84e-09
6. Felt that the severity of cluster headache affected your daily activities	0.688	0.483	0.821	5.63	39	38.2	2.42e-07
7. Been less involved in family affairs e.g. interaction with children, planning holidays	0.742	0.563	0.854	6.99	39	38.6	9.74e-09
8. Been unable to socialise/spend time with friends and family	0.636	0.39	0.793	5	39	29.2	1.11e-05
9. Been unable to achieve your daily goals and carry out routines and chores	0.681	0.475	0.817	5.43	39	39.2	3.04e-07
Impact on mood and interpersonal relationships							
10. Felt less respected by others	0.834	0.695	0.91	12.1	39	31	1.23e-10
11. Had problems with close personal relationship	0.843	0.723	0.914	11.5	39	39	3.33e-12
12. Felt you were a burden on family and friends	0.736	0.549	0.852	7.03	39	35	3e-08
13. Felt self-conscious and uncomfortable about your appearance after a cluster headache attack (e.g. swelling/redness of eyes and facial sweating, etc)	0.829	0.701	0.906	10.6	39	39.7	9.16e-12
14. Felt that others are dismissive of your cluster headaches	0.799	0.653	0.888	9.08	39	39.8	1.1e-10
15. Felt aggressive	0.911	0.838	0.952	21	39	39.2	8.59e-17
16. Felt bad about yourself, lost self-confidence or felt worthless	0.76	0.59	0.865	7.22	39	39.5	4.41e-09
17. Felt like harming yourself or suicidal	0.736	0.554	0.851	6.5	39	39.6	2.05e-08
18. Been irritable, impatient or less tolerant	0.706	0.508	0.833	5.72	39	39.5	1.32e-07

Item	Intraclass correlation coefficient	95% CI		F Test With True Value 0			
		Lower bound	Upper bound	Value	*df*1	*df2*	Sig
19. Been forgetful e.g. missed appointments	0.729	0.54	0.847	6.76	39	36.1	3.56e-08
20. Been unable to take care of your appearance (e.g. take a bath, put make-up on, change clothes, etc)	0.689	0.482	0.823	5.33	39	39.1	4.07e-07
21. Felt isolated, lonely or vulnerable	0.719	0.527	0.841	6	39	39	7.93e-08
Pain and anxiety							
22. Found your pain is unbearable if untreated	0.757	0.586	0.863	7.16	39	39.8	4.58e-09
23. Dreaded that the headache would not go away	0.685	0.45	0.826	6.07	39	26.5	3.42e-06
Lack of vitality							
24. Felt lacking in energy and constantly tired	0.748	0.57	0.858	7.24	39	37.6	8.17e-09
25. Felt sleepy, worn out or less able to concentrate due to nocturnal attacks of cluster headache	0.701	0.503	0.83	5.66	39	39.8	1.46e-07
26. Had problems concentrating e.g. reading paper, watching TV, etc	0.733	0.549	0.849	6.41	39	39.6	2.49e-08
27. Been unable to think clearly	0.715	0.522	0.838	5.95	39	39.7	7.33e-08
28. Felt tense or anxious	0.653	0.434	0.799	4.93	39	38.7	1.25e-06
How many times have you experienced a cluster headache attack during the last month?	0.993	0.987	0.996	290	39	39.7	7.23e-39
Please rate your overall satisfaction with your life by placing a vertical line on the scale below at an appropriate point	0.896	0.812	0.944	17.9	39	39.5	1.23e-15