

The Family Needs Questionnaire Revised- A Rasch analysis of measurement properties in the chronic phase after traumatic brain injury

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4 **The Family Needs Questionnaire-Revised: A Rasch analysis of measurement properties in the**
5 **chronic phase after traumatic brain injury**
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Abstract:**Purpose**

The main aim was to evaluate the measurement properties of the Family Needs Questionnaire-Revised (FNQ-R) in family members of individuals living with severe traumatic brain injury (TBI).

Methods

A total of 309 family members of individuals with severe TBI from Colombia, Denmark, Mexico, Norway and Spain participated. Rasch analysis of the FNQ-R and its 6 subscales was conducted.

Results

The Rasch analysis indicated a lack of fit of the 37-item FNQ-R to one single underlying construct of needs, and less than half of the items were invariant across the countries. Misfit of single items was revealed in the Need for Health Information, Need for Emotional Support, Need for Instrumental Support, Need for Professional Support and Need for Community Support Network subscales. Fit to the Rasch model was obtained after removal of misfitting items. The Involvement in Care subscale had too few items to be adequately assessed by the Rasch approach.

Conclusion

The FNQ-R is a well-targeted instrument for assessing the unmet needs of caregivers regarding the need for health information, emotional support, professional support and a community support network after some scoring adjustment and the removal of misfitting items. Caution should be taken when comparing responses across countries.

Keywords: traumatic brain injury, family needs, Rasch, measurement

Words: 3915

Introduction

Traumatic brain injury (TBI) is one of the main causes of disability worldwide (1), leaving family members and close relatives to struggle with the patient's physical disabilities and cognitive deficits as well as the management of behavioral issues and coordination of the patient's health services (2, 3). There is great variability in experience and needs among the individuals with TBI and their caregivers. The Family Needs Questionnaire (FNQ) was developed specifically to address the importance of specific needs and to what extent these needs were experienced to be met in caregivers of individuals with different types of acquired brain injuries (4, 5). A factor analysis of the questionnaire based on the importance of needs identified six factors (subscales): Health Information, Emotional Support, Instrumental Support, Professional Support, Community Support Network, and Involvement with Care (6). The FNQ was revised (FNQ-R) in 2008 based on the family members feedback, excluding the scoring of the importance of the needs (7). The questionnaire has been extensively used in the assessment of family needs after TBI, both in the early and later phases (7-10), and has been applied in longitudinal (11) and intervention studies (12-14). The content validity is well established, yet the factor structure has not been validated according to the met needs in the revised version. Furthermore, evaluation of the measurement properties according to new measurement theory has not been undertaken (15). In the field of rehabilitation, ordinal scales are often applied and summed up for scales or subscales with challenges in the scaling properties or redundancy of items, which may reduce the discriminative and responsiveness properties (16). Furthermore, measurements are likely to be applied across age groups, and gender and invariance to such factors are important for valid summation of scores in age and gender mixed populations (17). The FNQ-R has been translated to Spanish, Danish and Norwegian and has been applied in national studies (18). Although challenges and needs of family members after TBI are assumed to be rather universal, specific issues are shown to vary across

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4 cultures, health care systems and different family structures (18). However, whether cross-cultural
5 differences influence the measurement properties of the FNQ-R has not yet been evaluated.
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9 Thus, the purpose of this study was to evaluate the construct validity of the FNQ-R and its six
10 underlying dimensions **in family members of individuals living with severe TBI**. Furthermore, the
11 invariance of the measurement properties with respect to family members' age, gender and country
12 was explored.
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18 **Materials and methods**

19 *Procedures*

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Relatives of individuals with severe acquired brain injuries in five countries (Denmark, Spain, Colombia, Mexico and Norway) were invited to participate in this cross-sectional multi-country study.

Close adult family members (above 18 years of age) of patients with severe acquired brain injury were eligible for the study.

The close relative was chosen based on the patient's self-report or information in the patient's medical record or hospital registry.

Data collection was similar in all countries, with the questionnaires sent to the family members in the chronic phase, at least 12 months after the injury of the patient.

The timing and procedures for identification of the TBI subjects and their closest family member varied across countries.

The Colombian participants were included by telephone after discharge from rehabilitation to their home residence (19). The Danish participants were invited by letter after their family member had received subacute rehabilitation following acquired brain injury (20). The Mexican participants were identified based on the registry of patients with TBI treated at a rehabilitation hospital in

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4 Mexico City. The Norwegian participants were invited by letter after their family member had been
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6 admitted to one of the four trauma centers in Norway (11, 21). Finally, the Spanish family members
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8 were retrospectively contacted by telephone through the official Virgen de las Nieves Hospital
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10 patient registry of individuals with TBI discharged home after inpatient rehabilitation.
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12 Informed consent was obtained from all participating relatives, and research ethics committee
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14 approvals for the family member study were obtained in Norway (no 2009/702 D), Spain (CEI-
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16 08/10-02) and Mexico (#1310). In Colombia, the study was approved by the research committee at
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18 Universidad Javeriana de Cali, and in Denmark, the study was conducted according to the ethical
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20 guidelines approved by the Danish Protection Agency (2013-41-2007).
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27 *The Family Needs Questionnaire*

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30 The FNQ was developed to measure family members' perceived needs after the brain injury of a
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32 relative. Evidence of content validity was provided (22), and the instrument was deemed to have six
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34 independent subscales (6). In the revised version, 37 items retained in the subscales: 1) Need for
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36 Health Information (10 items); 2) Need for Emotional Support (8 items); 3) Need for Instrumental
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38 Support (6 items); 4) Need for a Community Support Network (5 items); 5) Need for Professional
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40 Support (5 items); and 6) Need for Involvement with Care (3 items). With permission from the
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42 original authors (Marwitz J.) The FNQ-R was translated into Danish, Spanish and Norwegian
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44 following recommended procedures (23).
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49 Each item was rated to indicate if the caregiver was satisfied that their needs were being met, and
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51 the response options were as follows: 1= yes (met), 2=partly (partly met) and 3=no (unmet).
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57 *Statistical Analyses*

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4 **Rasch analysis (24) the partial credit model (25)** was applied to evaluate the measurement
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6 properties of the FNQ-R and its six subscales. All dimensions and a total of 37 items were included
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8 in the analysis to evaluate whether these items share a common underlying construct of family
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10 needs. Subsequently, the information needs, emotional, instrumental, community, professional
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12 support and involvement in care dimensions of the six subscales were evaluated separately.
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15 All items were analyzed to determine the response level thresholds. If the threshold was disordered,
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17 i.e., the score levels did not separate the level of the underlying construct, the responses were
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19 rescored.
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22 Local dependency of the items was evaluated using a correlation analysis of the residuals of the
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24 items. A coefficient of 0.3 was chosen as the threshold value to indicate whether responses to two
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26 items were dependent on each other (26). Fit to the Rasch model was investigated for the items and
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28 individual participants, and overall summary fit (items and persons) for all 37 items in the FNQ-R
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30 and each of the six subscales are provided. The fit of the persons and items were reported on a logit
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32 scale as the means and SD, with a mean logit of 0 and an SD of 1 representing an optimal fit. The fit
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34 of the items was statistically evaluated using standardized residuals and chi-square statistics
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36 according to the weighted maximal likelihood method. Item residuals $< \pm 2.5$ with a non-significant
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38 chi-square probability value were considered to indicate an adequate fit to the Rasch **model (27)**.
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43 The overall summary fit of the FNQ and the subscales was evaluated using the chi-square item-trait
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45 interaction statistics (χ^2) (27). A non-significant probability value indicated a good fit to the Rasch
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47 model.
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51 Invariance across age, gender and country was examined using Differential Item Functioning (DIF)
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53 analysis. DIF is assessed by an analysis of variance for each item, comparing the scores across each
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55 level of age, gender and **nationality (28)**. Both significant main effects (uniform DIF) and
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57 interactions (non-uniform DIF) between age, gender and country were evaluated. For these
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4 analyses, age was dichotomized into groups $<$ and \geq 50 years, which was the median age. The F
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6 ratio (F) for the group difference and probability (p) were given for the DIF analysis. In the Rasch
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8 analysis, all items were ordered according to the expected level of met needs in the scale/subscale
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10 as a whole. DIF for an individual item represents a significantly different level of met needs across
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12 the trait values (age, gender or country here), such as a significantly different level of met needs on
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14 a specific item for men and women when men and women with the same overall level of met needs
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16 on the scale/subscale as a whole is compared.
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21 A test of unidimensionality was undertaken by creating two subsets of items with the most positive
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23 and most negative residuals according to Principal Component analysis, and personal estimates for
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25 each of the two subsets were calculated. To determine whether the two items for each person were
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27 significantly different, paired t-tests were performed (29). Similar estimates indicated the
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29 unidimensionality of the underlying construct. The number of t-tests with p values below 0.05 and
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31 the corresponding confidence intervals (CIs) were reported. The recommendation for a
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33 unidimensional construct is that the CI should include 0.05.
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38 The targeting of the FNQ-R and the six subscales were evaluated by examining the hierarchical
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40 distribution of the items and their response levels and was compared to the distribution of the
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42 patients along the same metric scale. Items distributed across the range of needs of the caregivers,
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44 with the majority of items matching the majority of persons, are deemed well targeted and will
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46 render a location close to zero.
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50 The Person Separation Reliability Index (PSI) is an estimate of the scale's internal consistency and
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52 the Rasch-based analogue to Cronbach's alpha (27). The PSI also provides an indication of the
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54 power of the measure to discriminate among persons with different levels of the trait. A value above
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56 0.8 was used to indicate differentiation across at least three groups of subjects.
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4 The Rasch analysis was performed in RUMM 2030 (RUMM laboratory, Perth, Australia). Other
5 analyses were performed using SPSS for Windows version 19.0 (NY, USA). A significance level of
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7 0.05 was adopted. This significance level was Bonferroni corrected according to the number of tests
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11 (30).
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16 **Results**

17 *Participants*

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19 A total of 588 caregivers were contacted (35 from Colombia, 74 from Denmark, 168 from Mexico,
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21 171 from Norway and 140 from Spain), and 309 caregivers completed the FNQ-R (29 from
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23 Colombia, 42 from Denmark, 67 from Mexico, 124 from Norway and 47 from Spain). The median
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25 time since injury was 32 months. The mean age of the caregivers was 50 (SD 13 years), and 80%
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27 were female; females were more prevalent across all five countries. The caregiver was the parent of
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29 the TBI patient in 40% of cases and was married to or a partner of the patient in 39% of the cases
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31 (Table 1). The mean age of the patients they cared for was 41 (SD 17 years). Only 11 patients from
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33 Denmark sustained a non-traumatic brain injury; other patients had sustained a TBI. The patients
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35 were living at home at the time of assessment of their family members in all countries except
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37 Denmark, where a minority of the patients were staying in nursing homes.
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45 *Rasch analysis of FNQ-R*

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47 The Rasch analysis of the FNQ-R revealed disordered thresholds in a total of nine of the 37 items
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49 (Table 2). The 37 items in the FNQ are scored on a 3-point Likert scale with the following response
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51 options: 1= yes (met), 2=partly (partly met), and 3=no (unmet). However, the scoring alternatives
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53 had to be reduced to unmet and met (i.e., partly met and unmet were collapsed) for nine of the items
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55 before further analyses. Collapsing partly met with unmet was based on the large overlap between
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4 these scoring options for most of the items. The revised scoring options are given for all items in
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6 Table 2.
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11 The 37-item FNQ-R did not fit the Rasch model after rescoring the 9 items with disordered
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13 thresholds ($\chi^2 = 310.39$, $p < 0.001$). All items were invariant to age. All items except item 2 were
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15 invariant to gender, but within this item, females reported a larger level of unmet needs regarding
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17 “To be told daily what was being done with the patient” (item 2). More than half of the items
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19 (n=23) showed DIF by country (Table 2), which may have contributed to misfit of the items. Items
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21 10, 11, 19, 21, 31, 32 and 33 had fit residuals outside ± 2.5 . However, fit to the Rasch model was
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23 still not reached after removing these. Positive as well as negative residual correlations (>0.3 or $<-$
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25 0.3) were revealed and appeared to explain this lack of fit. Removing all positively and negatively
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27 correlated items revealed fit to the Rasch model of only five items ($\chi^2 = 30.96$, $p = 0.06$) (Table 2)
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29 and a low power of analysis due to the sparse item number.
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36 *Rasch analysis of the FNQ-R subscales*

37 *Need for Health Information*

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39 The Need for Health Information subscale (10 items) did not fit the Rasch model ($\chi^2 = 162.98$,
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41 $p < 0.001$). Items 6, 10, 11 and 13 showed misfit with fit residuals outside ± 2.5 . After removing these
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43 four items, the remaining six items fit the Rasch model (Table 4). The uni-dimensionality of the six-
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45 item solution was also evaluated by the estimates of the most different items according to the PCA,
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47 which revealed that only 2 (CI 0.24 to 4.24) of the t-tests were below 5%, indicating fit to one
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49 single underlying unidimensional construct. The PSI was 0.70. Cronbach’s alpha was 0.57. There
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51 was no DIF by age or gender, whereas item 7, “Having questions answered honestly”, showed DIF
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53 by country. This item reflected a high level of met needs for Norwegian caregivers in relation to the
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4 expected level based on the overall needs for health information, whereas the other countries
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6 generally had lower than expected levels of met needs. The location of persons was 0.46 (SD 1.63),
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8 indicating that the caregivers revealed a slightly higher level of unmet needs than the target of the
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10 subscale (Figure 1). There was also a mismatch in the distribution of scoring options for the items,
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12 which was rather narrow compared to the range of needs reported by the patients, indicating
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14 potential floor and ceiling effects.
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20 *Need for Emotional support*

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22 The Need for Emotional Support subscale (8 items); did not fit the Rasch model ($\chi^2 = 130.85$,
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24 $p < 0.001$). Items 26 and 27 were misfit with fit residuals outside ± 2.5 . After removing these two
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26 items, the remaining six items fit the Rasch model (Table 4). The unidimensionality was also
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28 evaluated by the estimates of the most different items according to the PCA, which revealed that
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30 none of the t-tests were below 5%, indicating fit to one single underlying unidimensional construct.
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32 The PSI was 0.64. Cronbach's alpha was 0.49. There was no DIF by age or gender, and only item
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34 36 revealed DIF by country. The Norwegians and the Danes revealed a higher level of unmet needs
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36 regarding "Help preparing for the worst" (item 36) than expected relative to their overall level of
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38 emotional needs. The location of persons was 0.03 (SD 1.68), indicating that this subscale targeted
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40 the level of the caregivers' emotional needs well, but with too few scoring options to cover the
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42 spectrum of emotional needs (Figure 2).
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52 *Need for Instrumental Support*

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54 The Need for Instrumental Support subscale (6 items) did not fit the Rasch model ($\chi^2 = 47.08$,
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56 $p = 0.003$). Item 20 and item 21 showed misfit to the Rasch model with fit residuals outside ± 2.5 .
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4 After removing these two items, the remaining four items fit the Rasch model (Table 4). The
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6 unidimensionality was also evaluated by the estimates of the most different items according to the
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8 PCA, which revealed that none of the t-tests were below 5%, indicating fit to one single underlying
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10 unidimensional construct. The PSI was 0.58. Cronbach's alpha was 0.30. The estimates of the most
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12 different items according to the PCA revealed no significant differences, supporting fit to the Rasch
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14 model. All items were invariant to age and gender, whereas items 22 and 23 revealed DIF by
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16 country (Table 3). The Colombians differed by having a higher level of unmet needs regarding rest
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18 and sleep (item 22) than expected related to their overall need for support in this subscale. The
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20 Norwegians reported a higher level of unmet needs regarding breaks from responsibilities (item 23),
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22 relative to their general need for instrumental support, than the participants in the other countries.
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24 The location of persons was -0.32, SD 1.53, indicating that the caregivers had a higher level of met
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26 needs than the subscale target, and again, the scoring distribution was narrower than the needs
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28 distribution of the persons included (Figure 3).
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36 *Need for Professional Support*

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38 The Need for Professional Support subscale (5 items) did fit the Rasch model (Table 4). The
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40 unidimensionality was also evaluated by the estimates of the most different items according to the
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42 PCA, which revealed that none of the t-tests were below 5%, indicating fit to one single underlying
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44 unidimensional construct. The PSI was 0.55. Cronbach's alpha was 0.29. The estimates of the most
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46 different items according to the PCA revealed no significant differences, supporting fit to the Rasch
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48 model. All items were invariant to age and gender, but only item 14 was invariant to country. The
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50 Norwegians reported the highest level of unmet needs regarding advice for strange behavior,
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52 relative to the general level of professional support needs, with the Mexicans reporting the lowest
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54 level of unmet needs in this item (item 15). The Norwegians had clearly lower levels of unmet
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4 needs regarding how much the patients should do for themselves (item 17) relative what was
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6 expected from their overall unmet needs. Regarding resources to the patients, Mexico had a higher
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8 level of unmet needs (item 18) than expected. Additionally, the Norwegians had a higher level of
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10 unmet needs than expected, and Denmark had lower levels than expected, regarding resources for
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12 the caregivers themselves (item 19).
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15 The location of persons was 0.15, SD 1.27, indicating a rather good target with a slightly higher
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17 level of unmet needs by caregivers than by items, and there was a rather narrow distribution of
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19 scoring options (Figure 4).
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23 24 25 *Need for Community Support Network*

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27 The Need for a Community Support Network subscale (5 items) did not fit the Rasch model (χ^2
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29 =37.64, $p<0.01$).
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32 Item 29 had a high negative residual correlation indicating misfit, and after removing this item, fit
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34 to the Rasch model was obtained (Table 4). The unidimensionality was also evaluated by the
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36 estimates of the most different items according to the PCA, which revealed that none of the t-tests
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38 were below 5%, indicating fit to one single underlying unidimensional construct. The PSI was 0.36.
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40 Cronbach's alpha was 0.34. The estimates of the most different items according to the PCA
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42 revealed no significant differences, supporting fit to the Rasch model. All items were invariant to
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44 age and gender. Item 30 revealed DIF by country with the Mexicans clearly reported the lowest
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46 level of unmet needs regarding "To have the patient's employer, coworkers or teacher understand
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48 his/her problems" relative to the expected level given the overall needs of community support. The
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50 location of persons was 0.14, SD 1.07, indicating a rather good target with a slightly higher level of
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52 unmet needs by caregivers than by items, again, with a rather narrow range of scoring options
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57 (Figure 5).
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Need for Involvement with Care

The Need for Involvement with Care subscale items (3 items) all fit a unidimensional construct, therefore all items in the subscale were retained. T-tests for unidimensionality could not be performed with three items. Additionally, regarding The Need for Involvement of Care, three items were insufficient for an acceptable power of the fit analysis. All items were invariant for age, whereas females reported a larger level of unmet needs regarding being ‘told daily what was being done with the patient’ (item 2). This item also varied across countries, with Mexicans having the highest degree of met needs. Item 3, regarding “being able to give daily opinions regarding the patient”, also showed DIF by country, with the Colombians having the highest levels of met needs relative to the overall need for involvement in care.

Discussion

The FNQ-R overall scale did not fit the Rasch model with an acceptable number of items retained, which supports previous work indicating several underlying dimensions of needs (6). However, five of the previous six subscales representing the caregiver’s needs for health information, emotional support, professional support and a community support network revealed fit to the Rasch model after some modification of the included items (6). The sixth subscale, representing need for involvement in care, comprises only three items and showed the lowest Cronbach’s alpha in the previous conventional factor analysis approach (6). It was not possible to fit this subscale to the Rasch model due to the low number of items and scoring options. It is worth noting that all three items in this subscale revealed fit to an overall five-item solution of the FNQ-R, indicating consistency with the needs concept for these items. In the future, additional relevant items or expansion of the scoring options may provide a basis for establishing a valid subscale regarding

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4 involvement in care, which may be of major importance, particularly in the later phases after brain
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6 injury (31).
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11 The fit to the Rasch model indicated unidimensional underlying constructs for each of the other five
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13 subscales after removing the misfitting items. This unidimensionality was verified by the low level
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15 of statistically significant estimates for subsets of items within each subscale (29). This is in line
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17 with the high level of internal consistency in the subscales that was previously identified (6). It is
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19 worth noting that the previous analysis was based on the perceived importance of each item,
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21 whereas the present analyses were based on the met/unmet needs of the items. Furthermore, the
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23 present analysis was based on log transformation of the ordinal scoring options into interval scaling
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25 according to the recommendations for the statistical approach (32). Hence, the present results
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27 underscore the FNQ-R as a valid and robust measurement of the dimensions of family needs after
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29 TBI but do not support an overall sum score for the FNQ-R. The FNQ-R was developed to measure
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31 family members' perceived needs after brain injuries. The dominant participants in the present
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33 study were **family members** of persons with TBI, **and only a few patients had severe brain injury**
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35 **caused by nontraumatic causes**. However, previous studies do indicate that caregivers' needs are
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37 more closely related to the impairment level of the person in care than the underlying diagnosis
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39 (33). **The level of caregiving among the participants may have varied largely according to the needs**
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41 **of the patients, living situation and the professional support as well as cultural and health system**
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43 **differences**.
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50 The response options (met, partly met and unmet needs) rendered a relatively narrow range of
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52 scoring options. However, for nine of the items, only two valid scoring options were documented,
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54 and partly met and unmet needs had to be combined for these items. The choice of combining partly
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56 met and unmet needs was based on the distribution of these options showing the largest degree of
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4 overlap for the majority of items, and a universal solution for rescoring all items was sought.
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6 However, from a service perspective, one may argue for collapsing unmet and partly met needs due
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8 to both representing a need for additional care. This choice was not assumed to influence the results
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10 of the present analysis but could be important when the scales are applied to identify needs for
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12 further services in clinical practice. However, although the items of the different subscales targeted
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14 the present participants' needs rather well, the scaling of the subscales was narrow, rendering both
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16 floor and ceiling challenges of the measurements (34). It is worth noting that Kreutzer et al. (13)
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18 applied a 10-point scoring option for assessing needs in their intervention study. This scaling has
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20 not been validated in terms of reliability, discriminative validity or responsiveness. However, given
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22 the results of the present study, further development of the scoring options of the FNQ-R is highly
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24 warranted in order to use the scale in prospective and interventional studies. **The low PSI may be
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26 related to the scoring options but also to the low number of items included in each of the subscales.
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28 Cronbach's alpha, however, was calculated without imputation of missing values in the present
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30 study, and thus underestimated the internal consistency of the subscales. Hence, expanding or
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32 deleting items and collapsing subscales may also be a solution in the future development of the
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34 FNQ-R.**

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43 The FNQ-R was invariant across age and gender, except for women having a higher level of unmet
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45 need for "To be told daily what is being done with or for the patient" than men relative to their
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47 general level of unmet needs. However, the DIF across countries revealed in more than half of the
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49 items represents a large challenge for cross-cultural application and comparison. First, the DIF
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51 revealed in many of the items may have been a cause of their misfit to the Rasch model (35). We
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53 did not have a sufficient number of persons from each country to split items by country and
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55 reevaluate fit to the Rasch model. Furthermore, the specific country differences varied from item to
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4 item and involved many of the countries. Hence, simple mathematical solutions would be difficult
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6 to find. The FNQ-R has been used extensively in research on families after brain injury (8, 9), and
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8 cross-cultural validity is needed from a statistical point of view.
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11 Further studies are warranted to untangle the causes of the country differences and explore more
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13 robust wording or content of the items to render them more culturally invariant. Differences in the
14
15 patients' living situation and support could also influence the responses and interact with country
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17 differences. Better information of these factors should be focused in further studies. On the other
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19 hand, focusing too much on cultural invariance may cause removal of highly relevant needs items
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21 within specific countries or populations. With the development of web-based questionnaires,
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23 common items with additional country-specific items may be a feasible solution.
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26 27 *Conclusion*

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29 The present results clearly support the FNQ-R as a valid tool for measuring the Need for Health
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31 Information, Need for Emotional Support, Need for Instrumental Support, Need for Professional
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33 Support and Need for Community Support Network subscales. Expansion of items in the
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35 Involvement in Care subscale is recommended. The present study does not support the use of an
36
37 overall sum score for FNQ-R, and caution with cross-cultural comparison is advised due to the
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39 variance across countries in several of the items.
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52 53 **Disclosure**

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55 We have nothing to disclose.
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57 58 **Biographical note**

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42 injury.
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51 52 **References**

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55 1. Wilson L, Stewart W, Dams-O'Connor K, Diaz-Arrastia R, Horton L, Menon DK, et al. The
56 chronic and evolving neurological consequences of traumatic brain injury. *Lancet Neurol.* 2017;16(10):813-
57 25. doi: S1474-4422(17)30279-X [pii];10.1016/S1474-4422(17)30279-X [doi].
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2. Ponsford J, Draper K, Schonberger M. Functional outcome 10 years after traumatic brain injury: its relationship with demographic, injury severity, and cognitive and emotional status. *J Int Neuropsychol Soc.* 2008;14(2):233-42.
3. Andelic N, Sjøberg HL, Berntsen SA, Sigurdardottir S, Røe C. Self-perceived health care needs and delivery of health care services 5 years after moderate-to-severe traumatic brain injury. *PM&R.* 2014;6(11):1013-21. doi: <http://dx.doi.org/10.1016/j.pmrj.2014.05.005>.
4. Kreutzer JW, P. *Community Integration Following Traumatic Brain Injuries.* Baltimore: Brookes; 1990.
5. Kreutzer J, Bergquist S. Family needs after brain injury. A quantitative analysis. *J Head Trauma Rehabil.* 1994;9(3):104-15.
6. Serio CD, Kreutzer JS, Witol AD. Family needs after traumatic brain injury: a factor analytic study of the Family Needs Questionnaire. *Brain Inj.* 1997;11(1):1-9.
7. Kreutzer JS, Marwitz JH, Klyce DW, Wilder Schaaf KP, Sima AP, Welch AM, et al. Family Needs on an Inpatient Brain Injury Rehabilitation Unit: A Quantitative Assessment. *J Head Trauma Rehabil.* 2018;33(4):228-36. doi: 10.1097/HTR.0000000000000390. PubMed PMID: 29601345.
8. Witol AD, Sander AM, Kreutzer JS. A longitudinal analysis of family needs following traumatic brain injury. *NeuroRehabilitation.* 1996;7(3):175-87. doi: 10.3233/NRE-1996-7303. PubMed PMID: 24525887.
9. Kolakowsky-Hayner SA, Miner KD, Kreutzer JS. Long-term life quality and family needs after traumatic brain injury. *J Head Trauma Rehabil.* 2001;16(4):374-85.
10. Moules S, Chandler BJ. A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain injury.* 1999;13(12):983-93. PubMed PMID: 10628503.
11. Anke A, Roe C, Sigurdardottir S, Norup A, Soberg HL, Arango-Lasprilla JC, et al. Family needs at one and two years after severe traumatic brain injury: a prospective study of changes and predictors. *Brain injury.* 2020;34(1):89-97. Epub 2019/10/28. doi: 10.1080/02699052.2019.1682191. PubMed PMID: 31647690.
12. Stebbins P, Leung P. Changing family needs after brain injury. *J Rehabil.* 1998;64(4):15-22. PubMed PMID: WOS:000077123300004.
13. Kreutzer JS, Marwitz JH, Sima AP, Godwin EE. Efficacy of the Brain Injury Family Intervention: Impact on Family Members. *J Head Trauma Rehabil.* 2015;30(4):249-60. doi: 10.1097/HTR.0000000000000144. PubMed PMID: 26147315.
14. Niemeier JP, Kreutzer JS, Marwitz JH, Sima AP. A Randomized Controlled Pilot Study of a Manualized Intervention for Caregivers of Patients With Traumatic Brain Injury in Inpatient Rehabilitation. *Arch Phys Med Rehabil.* 2019;100(4S):S65-S75. doi: 10.1016/j.apmr.2018.07.422. PubMed PMID: 30075147.
15. Terwee CB, Mokkink LB, Knol DL, Ostelo RW, Bouter LM, de Vet HC. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation.* 2012;21(4):651-7. doi: 10.1007/s11136-011-9960-1. PubMed PMID: 21732199; PubMed Central PMCID: PMC3323819.
16. Lindeboom R, Vermeulen M, Holman R, De Haan RJ. Activities of daily living instruments: optimizing scales for neurologic assessments. *Neurology.* 2003;60(5):738-42. doi: 10.1212/01.wnl.0000044402.16315.fc. PubMed PMID: 12630419.
17. Nakken N, Janssen DJ, van VM, de Vries GJ, Clappers-Gielen GA, Michels AJ, et al. Gender differences in partners of patients with COPD and their perceptions about the patients. *Int J Chron Obstruct Pulmon Dis.* 2017;12:95-104. doi: 10.2147/COPD.S118871 [doi];copd-12-095 [pii].
18. Norup A, Perrin PB, Cuberos-Urbano G, Anke A, Andelic N, Doyle ST, et al. Family needs after brain injury: A cross cultural study. *Neurorehabilitation.* 2015;36(2):203-14. doi: NRE1208 [pii];10.3233/NRE-151208 [doi].

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19. Arango-Lasprilla JC, Quijano MC, Aponte M, Cuervo MT, Nicholls E, Rogers HL, et al. Family needs in caregivers of individuals with traumatic brain injury from Colombia, South America. *Brain injury*. 2010;24(7-8):1017-26. doi: 10.3109/02699052.2010.490516. PubMed PMID: 20545455.
20. Doser K, Norup A. Family needs in the chronic phase after severe brain injury in Denmark. *Brain Inj*. 2014;28(10):1230-7. doi: 10.3109/02699052.2014.915985 [doi].
21. Manskow US, Arntzen C, Damsgård E, Braine M, Sigurdardottir S, Andelic N, et al. Family members' experience with in-hospital health care after severe traumatic brain injury: a national multicentre study. *BMC Health Services Research*. 2018;8(951):10. doi: <http://dx.doi.org/10.1186/s12913-018-3773-7>.
22. Kreutzer JS, Rapport LJ, Marwitz JH, Harrison-Felix C, Hart T, Glenn M, et al. Caregivers' well-being after traumatic brain injury: a multicenter prospective investigation. *ArchPhysMedRehabil*. 2009;90(6):939-46.
23. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol*. 1993;46(12):1417-32.
24. Rasch G. Probabilistic models for some intelligence and attainment tests. Chicago, USA: University of Chicago Press; 1960 1960.
25. Masters G. A Rasch model for partial credit scoring. *Psychometrika*. 1982;47:149-74.
26. Wright BD, Mok M. Rasch models overview. *JApplMeas*. 2000;1(1):83-106.
27. Andrich D. Rasch models for measurements. *Quantitative Application in Social Sciences*. London: Sage; 1988.
28. Angoff WH. Perspectives on differential item functioning methodology. In: . HPW, Weiner H, editors. *Differential item functioning*. Mahwah, New Jersey, USA: Lawrence Erlbaum; 1993. p. 3-23.
29. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis Rheum*. 2007;57(8):1358-62. Epub 2007/12/01. doi: 10.1002/art.23108. PubMed PMID: 18050173.
30. Bland JM, Altman DG. Multiple significance tests: the Bonferroni method. *Br Med J*. 1995;310:170.
31. Fisher A, Bellon M, Lawn S, Lennon S, Sohlberg M. Family-directed approach to brain injury (FAB) model: a preliminary framework to guide family-directed intervention for individuals with brain injury. *Disabil Rehabil*. 2019;41(7):854-60. doi: 10.1080/09638288.2017.1407966. PubMed PMID: 29171308.
32. Grimby G, Tennant A, Tesio L. The use of raw scores from ordinal scales: time to end malpractice? *J Rehabil Med*. 2012;44(2):97-8. doi: 10.2340/16501977-0938. PubMed PMID: 22334345.
33. Tramonti F, Bonfiglio L, Bongioanni P, Belviso C, Fanciullacci C, Rossi B, et al. Caregiver burden and family functioning in different neurological diseases. *Psychology, health & medicine*. 2019;24(1):27-34. doi: 10.1080/13548506.2018.1510131. PubMed PMID: 30141703.
34. McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are available health status surveys adequate? *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 1995;4(4):293-307. PubMed PMID: 7550178.
35. Hagquist C, Andrich D. Recent advances in analysis of differential item functioning in health research using the Rasch model. *Health Qual Life Outcomes*. 2017;15(1):181. doi: 10.1186/s12955-017-0755-0. PubMed PMID: 28927468; PubMed Central PMCID: PMC5606090.

Figure legends (Five figures)

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4 **Fig 1.** Distribution of the scores for the six items of the Need for Health Information subscale of *the*
5 Family Needs Questionnaire-Revised with fit to a unidimensional construct and the scores of family
6 members of patients with traumatic brain injury on the same logit scale. N=307, Persons location
7 mean 0.46, SD 1.63.
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15 **Fig 2.** Distribution of the scores for the six items of the Need for Emotional Support subscale of the
16 Family Needs Questionnaire-Revised with fit to a unidimensional construct and the scores for the
17 family member of patients with traumatic brain injury on the same logit scale. N=305, Persons
18 location mean 0.03, SD 1.68.
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28 **Fig 3.** Distribution of the scores for the four items of the Need for Instrumental Support subscale of
29 the Family Needs Questionnaire Revised with fit to a unidimensional construct and the scores for
30 the family member of patients with traumatic brain injury on the same logit scale. N=305, Persons
31 location mean -0.32, SD 1.53.
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41 **Fig 4.** Distribution of the scores for the 5 items of the Need for Professional Support subscale of the
42 Family Needs Questionnaire Revised with fit to a unidimensional construct and the scores for the
43 family member of patients with traumatic brain injury on the same logit scale. N=303, Persons
44 location mean 0.15, SD 1.27.
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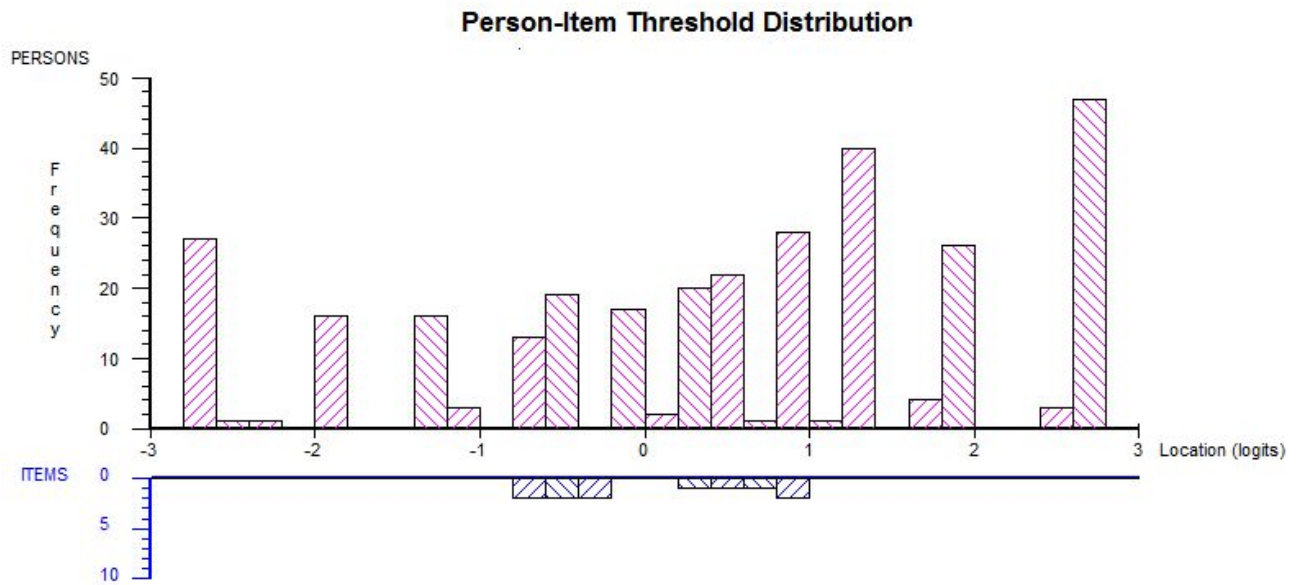
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Fig 5. Distribution of the scores for the four items of the Need for Community Support Network subscale of the Family Needs Questionnaire Revised with fit to a unidimensional construct and the scores for the family member of patients with traumatic brain injury on the same logit scale. N=306, Persons location mean 0.14, SD 1.07.

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10 **Figures**

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13 **Fig1.**



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63 **Fig2.**

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Fig3.

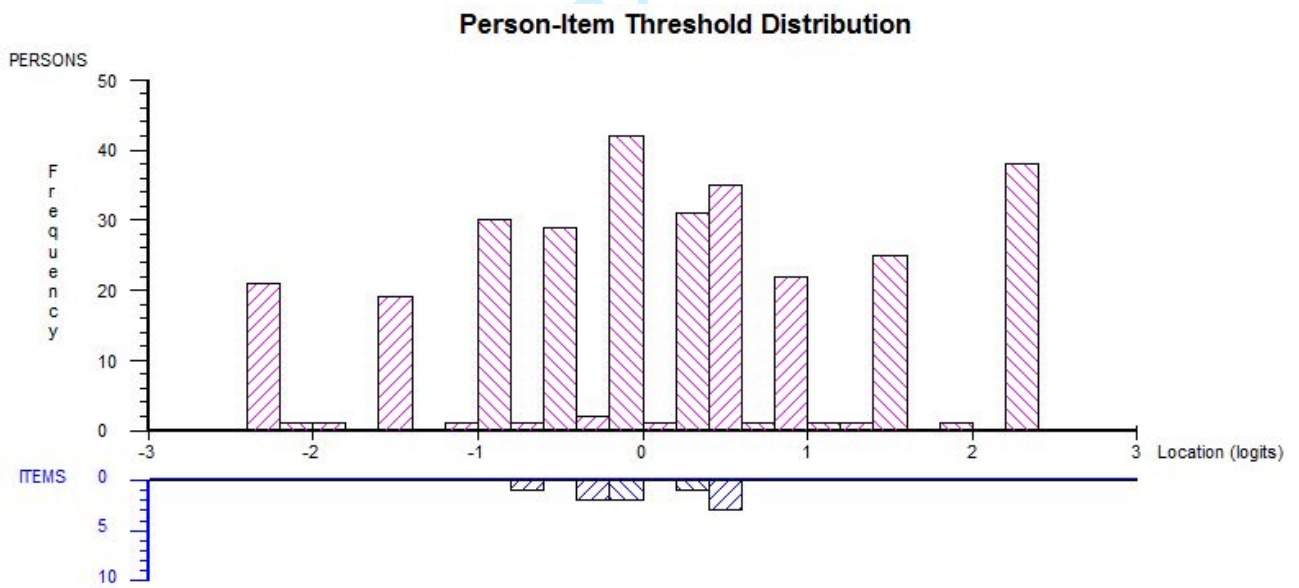
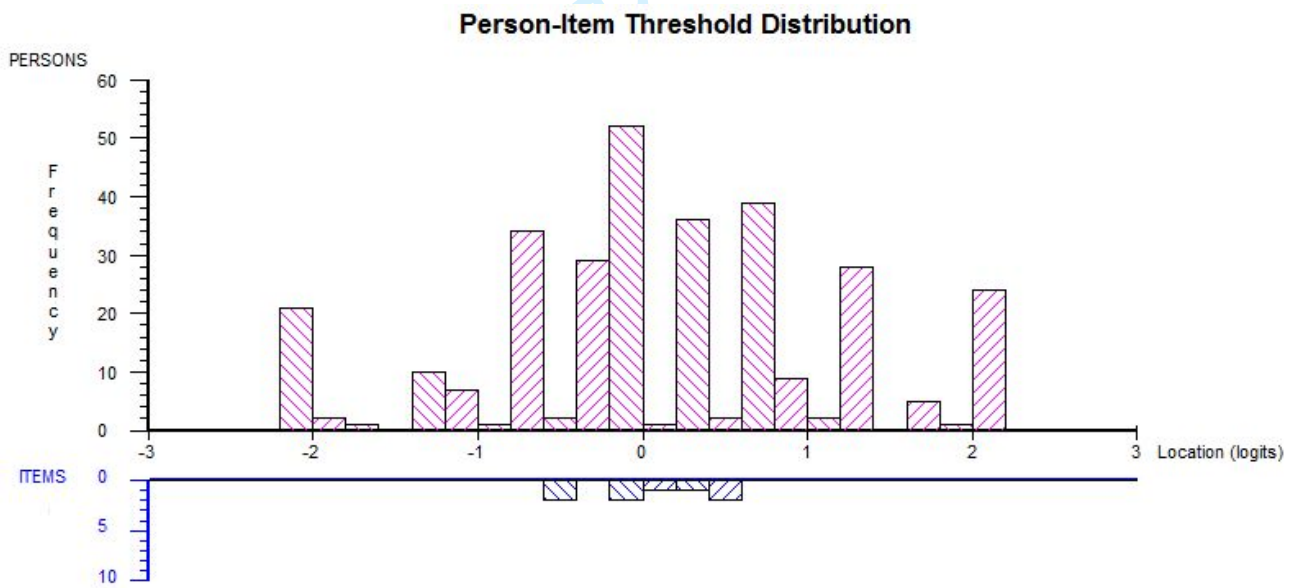


Fig4.

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Fig5.



Tables

Table 1. Demographic characteristics of the close family member

Country	Age Years (SD)	Gender (% female)	Married/ Cohabitant %	Parents %	Siblings %	Children %	Other %
Columbia	40 (16)	66%	28%	14%	35%	10%	13%
Denmark	53 (12)	76%	38%	41%	5%	12%	4%
Mexico	51 (13)	82%	27%	52%	15%	3%	3%
Norway	51 (11)	86%	44%	41%	9%	4%	2%
Spain	49 (12)	77%	49%	36%	2%	13%	0%

Table 2.

The 37 items in the Family Needs Questionnaire-Revised numbered according to sequence in the questionnaire and grouped according to the subscale belonging.

<i>Need for Health Information</i>	<i>Item score</i>
1. To be shown that medical, educational or rehabilitation staff respect the patient's needs and wishes	1,2,3
4. To be told about all changes in the patient's medical status*	1,2,3
5. To be assured that the best possible medical care is being given to the patient	1,2,3
6. To have explanations from professionals given in terms I can understand#	1,2
7. To have my questions answered honestly#	1,2
10. To have complete information on the medical care of traumatic injuries	1,2
11. To have complete information on the patient's physical problems	1,2,3
12. To have complete information on the patient's problems in thinking	1,2,3
13. To have complete information on drug and alcohol problems and treatment#	1,2
16. To have information on the patient's rehabilitative or educational process#	1,2,3
<i>Need for Emotional Support</i>	
26. To have my significant other understand how difficult it is for me#	1,2,3
27. To have my partners or friends understand how difficult it is for me#	1,2,3
31. To discuss my feelings about the patient with someone who has gone through the same experience#	1,2
33. To be reassured that it is usual to have strong negative feelings about the patient#	1,2
34. Help getting over my doubts and fears about the future#	1,2,3
35. Help remaining hopeful about the patient's future	1,2,3
36. Help preparing for the worst#	1,2
37. To be encouraged to ask others to help out	1,2,3

<i>Need for Instrumental Support</i>		
20. To have help keeping the house#		1,2
21. To have help from other members of the family in taking care of the patient#		1,2,3
22. To get enough rest or sleep#		1,2,3
23. To get a break from my problems and responsibilities#		1,2,3
24. To spend time with my friends#		1,2,3
25. To pay attention to my own needs, job or interests		1,2,3
<i>Need for Professional Support</i>		
14. To be told how long each of the patient's problems is expected to last		1,2,3
15. To be shown what to do when the patient is upset or acting strange#		1,2
17. To have help in deciding how much to let the patient do by himself/herself*#		1,2,3
18. To have enough resources for the patient#		1,2,3
19. To have enough resources for myself or the family#		1,2,3
<i>Need for Community Support Network</i>		
9. To have a professional to turn to for advice or services when the patient needs help		1,2,3
28. To have other family members understand the patient's problems#		1,2,3
29. To have the patient's friends understand his/her problems#		1,2,3
30. To have the patient's employer, coworkers or teacher understand his/her problems#		1,2,3
32. To discuss my feelings about the patient with other friends or family#		1,2,3
<i>Involvement with Care</i>		
2. To be told daily what is being done with or for the patient*#		1,2,3
3. To give my opinions daily to others involved in the patient's care, rehabilitation or education*#		1,2,3
8. To be shown that my opinions are used planning the patient's treatment, rehabilitation or education*		1,2,3

*Items fitting the Rasch model for the overall FNQ. # Items with DIF by Country. The score of the individual items provided according to the scoring alternatives 1=met, 2=partly met, and 3=unmet, or for the five items with disordered threshold 1=met and 2=partly met/unmet. The revised scoring options are given for all items.

Table 3.

The items of the five subscales in the Family Needs Questionnaire-Revised fitting the Rasch model in the five subscales analyzed with Location, standard error of location (SE) and Fit residual of the individual items.

<i>Need for Health Information</i>	<i>Location</i>	<i>SE</i>	<i>Fit Resid</i>
1. To be shown that medical, educational or rehabilitation staff respect the patient's needs and wishes	0.15	0.11	1.07
4. To be told about all changes in the patient's medical status	-0.06	0.11	-1.25
5. To be assured that the best possible medical care is being given to the patient	0.30	0.11	-0.51
7. To have my questions answered honestly#	-0.64	0.16	-0.78
12. To have complete information on the patient's problems in thinking	0.33	0.11	1.90
16. To have information on the patient's rehabilitative or educational process	-0.08	0.11	0.89
<i>Need for Emotional Support</i>			
31. To discuss my feelings about the patient with someone who has gone through the same experience	-0.85	0.17	1.77

33. To be reassured that it is usual to have strong negative feelings about the patient	-0.24	0.16	1.51
34. Help getting over my doubts and fears about the future	0.28	0.11	0.35
35. Help remaining hopeful about the patient's future	0.43	0.11	-1.29
36. Help preparing for the worst#	0.06	0.16	-1.11
37. To be encouraged to ask others to help out	0.33	0.11	0.08
<i>Need for Instrumental Support</i>			
22. To get enough rest or sleep#	-0.34	0.11	0.52
23. To get a break from my problems and responsibilities#	0.19	0.10	1.64
24. To spend time with my friends	0.32	0.11	-0.46
25. To pay attention to my own needs, job or interests	-0.17	0.17	0.88
<i>Need for Professional Support</i>			
14. To be told how long each of the patient's problems is expected to last	0.04	0.10	0.55
15. To be shown what to do when the patient is upset or acting strange#	-0.17	0.14	2.06
17. To have help in deciding how much to let the patient do by himself/herself#	0.06	0.10	0.26
18. To have enough resources for the patient#	-0.35	0.09	-0.09
19. To have enough resources for myself or the family#	0.42	0.09	1.64
<i>Need for Community Support Network</i>			
9. To have a professional to turn to for advice or services when the patient needs help	-0.10	0.09	1.33
28. To have other family members understand the patient's problems	-0.05	0.09	0.20
29. To have the patient's friends understand his/her problems	0.25	0.10	1.69
30. To have the patient's employer, coworkers or teacher understand his/her problems#	-0.11	0.09	1.57

#Items with DIF by Country when analyzed in the subscales

Table 4.

The five subscales in the Family Needs Questionnaire-Revised with sufficient items to be fitted to the Rasch model with Chi –square (X^2) and p value for the subscale and Fit of persons and items for each subscale.

<i>Subscale (Chi-square and p-value)</i>	<i>Fit of persons</i>		<i>Fit of items</i>	
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>
<i>Need for Health Information</i> ($X^2 = 31.40$, $p=0.14$)	-0.26	1.24	0.22	1.24
<i>Need for Emotional Support</i> ($X^2 = 33.59$, $p=0.09$)	-0.18	1.05	0.12	0.15
<i>Need for Instrumental Support</i> ($X^2 = 22.65$, $p=0.12$).	-0.37	1.44	0.65	0.87
<i>Need for Professional Support</i> ($X^2 = 23.64$, $p=0.26$)	-0.09	1.05	0.88	0.92
<i>Need for Community Support Network</i> ($X^2 = 21.27$, $p=0.17$)	-0.28	1.82	1.20	1.68

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The Family Needs Questionnaire-Revised: A Rasch analysis of measurement properties in the chronic phase after traumatic brain injury

For Peer Review Only

Abstract:**Purpose**

The main aim was to evaluate the measurement properties of the Family Needs Questionnaire-Revised (FNQ-R) in family members of individuals living with severe traumatic brain injury (TBI).

Methods

A total of 309 family members of individuals with severe TBI from Colombia, Denmark, Mexico, Norway and Spain participated. Rasch analysis of the FNQ-R and its 6 subscales was conducted.

Results

The Rasch analysis indicated a lack of fit of the 37-item FNQ-R to one single underlying construct of needs, and less than half of the items were invariant across the countries. Misfit of single items was revealed in the Need for Health Information, Need for Emotional Support, Need for Instrumental Support, Need for Professional Support and Need for Community Support Network subscales. Fit to the Rasch model was obtained after removal of misfitting items. The Involvement in Care subscale had too few items to be adequately assessed by the Rasch approach.

Conclusion

The FNQ-R is a well-targeted instrument for assessing the unmet needs of caregivers regarding the need for health information, emotional support, professional support and a community support network after some scoring adjustment and the removal of misfitting items. Caution should be taken when comparing responses across countries.

Keywords: traumatic brain injury, family needs, Rasch, measurement

Words: 3915

Introduction

Traumatic brain injury (TBI) is one of the main causes of disability worldwide (1), leaving family members and close relatives to struggle with the patient's physical disabilities and cognitive deficits as well as the management of behavioral issues and coordination of the patient's health services (2, 3). There is great variability in experience and needs among the individuals with TBI and their caregivers. The Family Needs Questionnaire (FNQ) was developed specifically to address the importance of specific needs and to what extent these needs were experienced to be met in caregivers of individuals with different types of acquired brain injuries (4, 5). A factor analysis of the questionnaire based on the importance of needs identified six factors (subscales): Health Information, Emotional Support, Instrumental Support, Professional Support, Community Support Network, and Involvement with Care (6). The FNQ was revised (FNQ-R) in 2008 based on the family members feedback, excluding the scoring of the importance of the needs (7). The questionnaire has been extensively used in the assessment of family needs after TBI, both in the early and later phases (7-10), and has been applied in longitudinal (11) and intervention studies (12-14). The content validity is well established, yet the factor structure has not been validated according to the met needs in the revised version. Furthermore, evaluation of the measurement properties according to new measurement theory has not been undertaken (15). In the field of rehabilitation, ordinal scales are often applied and summed up for scales or subscales with challenges in the scaling properties or redundancy of items, which may reduce the discriminative and responsiveness properties (16). Furthermore, measurements are likely to be applied across age groups, and gender and invariance to such factors are important for valid summation of scores in age and gender mixed populations (17). The FNQ-R has been translated to Spanish, Danish and Norwegian and has been applied in national studies (18). Although challenges and needs of family members after TBI are assumed to be rather universal, specific issues are shown to vary across

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4 cultures, health care systems and different family structures (18). However, whether cross-cultural
5 differences influence the measurement properties of the FNQ-R has not yet been evaluated.
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9 Thus, the purpose of this study was to evaluate the construct validity of the FNQ-R and its six
10 underlying dimensions **in family members of individuals living with severe TBI**. Furthermore, the
11 invariance of the measurement properties with respect to family members' age, gender and country
12 was explored.
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18 **Materials and methods**

19 *Procedures*

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Relatives of individuals with severe acquired brain injuries in five countries (Denmark, Spain, Colombia, Mexico and Norway) were invited to participate in this cross-sectional multi-country study.

Close adult family members (above 18 years of age) of patients with severe acquired brain injury were eligible for the study.

The close relative was chosen based on the patient's self-report or information in the patient's medical record or hospital registry.

Data collection was similar in all countries, with the questionnaires sent to the family members in the chronic phase, at least 12 months after the injury of the patient.

The timing and procedures for identification of the TBI subjects and their closest family member varied across countries.

The Colombian participants were included by telephone after discharge from rehabilitation to their home residence (19). The Danish participants were invited by letter after their family member had received subacute rehabilitation following acquired brain injury (20). The Mexican participants were identified based on the registry of patients with TBI treated at a rehabilitation hospital in

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4 Mexico City. The Norwegian participants were invited by letter after their family member had been
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6 admitted to one of the four trauma centers in Norway (11, 21). Finally, the Spanish family members
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8 were retrospectively contacted by telephone through the official Virgen de las Nieves Hospital
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10 patient registry of individuals with TBI discharged home after inpatient rehabilitation.
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12 Informed consent was obtained from all participating relatives, and research ethics committee
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14 approvals for the family member study were obtained in Norway (no 2009/702 D), Spain (CEI-
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16 08/10-02) and Mexico (#1310). In Colombia, the study was approved by the research committee at
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18 Universidad Javeriana de Cali, and in Denmark, the study was conducted according to the ethical
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20 guidelines approved by the Danish Protection Agency (2013-41-2007).
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27 *The Family Needs Questionnaire*

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30 The FNQ was developed to measure family members' perceived needs after the brain injury of a
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32 relative. Evidence of content validity was provided (22), and the instrument was deemed to have six
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34 independent subscales (6). In the revised version, 37 items retained in the subscales: 1) Need for
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36 Health Information (10 items); 2) Need for Emotional Support (8 items); 3) Need for Instrumental
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38 Support (6 items); 4) Need for a Community Support Network (5 items); 5) Need for Professional
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40 Support (5 items); and 6) Need for Involvement with Care (3 items). With permission from the
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42 original authors (Marwitz J.) The FNQ-R was translated into Danish, Spanish and Norwegian
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44 following recommended procedures (23).
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49 Each item was rated to indicate if the caregiver was satisfied that their needs were being met, and
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51 the response options were as follows: 1= yes (met), 2=partly (partly met) and 3=no (unmet).
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57 *Statistical Analyses*

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4 **Rasch analysis (24) the partial credit model (25)** was applied to evaluate the measurement
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6 properties of the FNQ-R and its six subscales. All dimensions and a total of 37 items were included
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8 in the analysis to evaluate whether these items share a common underlying construct of family
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10 needs. Subsequently, the information needs, emotional, instrumental, community, professional
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12 support and involvement in care dimensions of the six subscales were evaluated separately.
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15 All items were analyzed to determine the response level thresholds. If the threshold was disordered,
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17 i.e., the score levels did not separate the level of the underlying construct, the responses were
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19 rescored.
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22 Local dependency of the items was evaluated using a correlation analysis of the residuals of the
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24 items. A coefficient of 0.3 was chosen as the threshold value to indicate whether responses to two
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26 items were dependent on each other (26). Fit to the Rasch model was investigated for the items and
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28 individual participants, and overall summary fit (items and persons) for all 37 items in the FNQ-R
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30 and each of the six subscales are provided. The fit of the persons and items were reported on a logit
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32 scale as the means and SD, with a mean logit of 0 and an SD of 1 representing an optimal fit. The fit
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34 of the items was statistically evaluated using standardized residuals and chi-square statistics
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36 according to the weighted maximal likelihood method. Item residuals $< \pm 2.5$ with a non-significant
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38 chi-square probability value were considered to indicate an adequate fit to the Rasch **model (27)**.
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43 The overall summary fit of the FNQ and the subscales was evaluated using the chi-square item-trait
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45 interaction statistics (χ^2) (27). A non-significant probability value indicated a good fit to the Rasch
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47 model.
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51 Invariance across age, gender and country was examined using Differential Item Functioning (DIF)
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53 analysis. DIF is assessed by an analysis of variance for each item, comparing the scores across each
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55 level of age, gender and **nationality (28)**. Both significant main effects (uniform DIF) and
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57 interactions (non-uniform DIF) between age, gender and country were evaluated. For these
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4 analyses, age was dichotomized into groups $<$ and \geq 50 years, which was the median age. The F
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6 ratio (F) for the group difference and probability (p) were given for the DIF analysis. In the Rasch
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8 analysis, all items were ordered according to the expected level of met needs in the scale/subscale
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10 as a whole. DIF for an individual item represents a significantly different level of met needs across
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12 the trait values (age, gender or country here), such as a significantly different level of met needs on
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14 a specific item for men and women when men and women with the same overall level of met needs
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16 on the scale/subscale as a whole is compared.
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21 A test of unidimensionality was undertaken by creating two subsets of items with the most positive
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23 and most negative residuals according to Principal Component analysis, and personal estimates for
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25 each of the two subsets were calculated. To determine whether the two items for each person were
26
27 significantly different, paired t-tests were performed (29). Similar estimates indicated the
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29 unidimensionality of the underlying construct. The number of t-tests with p values below 0.05 and
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31 the corresponding confidence intervals (CIs) were reported. The recommendation for a
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33 unidimensional construct is that the CI should include 0.05.
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38 The targeting of the FNQ-R and the six subscales were evaluated by examining the hierarchical
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40 distribution of the items and their response levels and was compared to the distribution of the
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42 patients along the same metric scale. Items distributed across the range of needs of the caregivers,
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44 with the majority of items matching the majority of persons, are deemed well targeted and will
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46 render a location close to zero.
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50 The Person Separation Reliability Index (PSI) is an estimate of the scale's internal consistency and
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52 the Rasch-based analogue to Cronbach's alpha (27). The PSI also provides an indication of the
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54 power of the measure to discriminate among persons with different levels of the trait. A value above
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56 0.8 was used to indicate differentiation across at least three groups of subjects.
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4 The Rasch analysis was performed in RUMM 2030 (RUMM laboratory, Perth, Australia). Other
5 analyses were performed using SPSS for Windows version 19.0 (NY, USA). A significance level of
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7 0.05 was adopted. This significance level was Bonferroni corrected according to the number of tests
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11 (30).
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16 **Results**

17 *Participants*

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19 A total of 588 caregivers were contacted (35 from Colombia, 74 from Denmark, 168 from Mexico,
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21 171 from Norway and 140 from Spain), and 309 caregivers completed the FNQ-R (29 from
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23 Colombia, 42 from Denmark, 67 from Mexico, 124 from Norway and 47 from Spain). The median
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25 time since injury was 32 months. The mean age of the caregivers was 50 (SD 13 years), and 80%
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27 were female; females were more prevalent across all five countries. The caregiver was the parent of
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29 the TBI patient in 40% of cases and was married to or a partner of the patient in 39% of the cases
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31 (Table 1). The mean age of the patients they cared for was 41 (SD 17 years). Only 11 patients from
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33 Denmark sustained a non-traumatic brain injury; other patients had sustained a TBI. The patients
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35 were living at home at the time of assessment of their family members in all countries except
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37 Denmark, where a minority of the patients were staying in nursing homes.
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45 *Rasch analysis of FNQ-R*

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47 The Rasch analysis of the FNQ-R revealed disordered thresholds in a total of nine of the 37 items
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49 (Table 2). The 37 items in the FNQ are scored on a 3-point Likert scale with the following response
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51 options: 1= yes (met), 2=partly (partly met), and 3=no (unmet). However, the scoring alternatives
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53 had to be reduced to unmet and met (i.e., partly met and unmet were collapsed) for nine of the items
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55 before further analyses. Collapsing partly met with unmet was based on the large overlap between
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4 these scoring options for most of the items. The revised scoring options are given for all items in
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6 Table 2.
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11 The 37-item FNQ-R did not fit the Rasch model after rescoring the 9 items with disordered
12 thresholds ($\chi^2 = 310.39$, $p < 0.001$). All items were invariant to age. All items except item 2 were
13 invariant to gender, but within this item, females reported a larger level of unmet needs regarding
14 “To be told daily what was being done with the patient” (item 2). More than half of the items
15 (n=23) showed DIF by country (Table 2), which may have contributed to misfit of the items. Items
16 10, 11, 19, 21, 31, 32 and 33 had fit residuals outside ± 2.5 . However, fit to the Rasch model was
17 still not reached after removing these. Positive as well as negative residual correlations (>0.3 or $<-$
18 0.3) were revealed and appeared to explain this lack of fit. Removing all positively and negatively
19 correlated items revealed fit to the Rasch model of only five items ($\chi^2 = 30.96$, $p = 0.06$) (Table 2)
20 and a low power of analysis due to the sparse item number.
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36 *Rasch analysis of the FNQ-R subscales*

37 *Need for Health Information*

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39 The Need for Health Information subscale (10 items) did not fit the Rasch model ($\chi^2 = 162.98$,
40 $p < 0.001$). Items 6, 10, 11 and 13 showed misfit with fit residuals outside ± 2.5 . After removing these
41 four items, the remaining six items fit the Rasch model (Table 4). The uni-dimensionality of the six-
42 item solution was also evaluated by the estimates of the most different items according to the PCA,
43 which revealed that only 2 (CI 0.24 to 4.24) of the t-tests were below 5%, indicating fit to one
44 single underlying unidimensional construct. The PSI was 0.70. Cronbach's alpha was 0.57. There
45 was no DIF by age or gender, whereas item 7, “Having questions answered honestly”, showed DIF
46 by country. This item reflected a high level of met needs for Norwegian caregivers in relation to the
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4 expected level based on the overall needs for health information, whereas the other countries
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6 generally had lower than expected levels of met needs. The location of persons was 0.46 (SD 1.63),
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8 indicating that the caregivers revealed a slightly higher level of unmet needs than the target of the
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10 subscale (Figure 1). There was also a mismatch in the distribution of scoring options for the items,
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12 which was rather narrow compared to the range of needs reported by the patients, indicating
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14 potential floor and ceiling effects.
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20 *Need for Emotional support*

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22 The Need for Emotional Support subscale (8 items); did not fit the Rasch model ($\chi^2 = 130.85$,
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24 $p < 0.001$). Items 26 and 27 were misfit with fit residuals outside ± 2.5 . After removing these two
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26 items, the remaining six items fit the Rasch model (Table 4). The unidimensionality was also
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28 evaluated by the estimates of the most different items according to the PCA, which revealed that
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30 none of the t-tests were below 5%, indicating fit to one single underlying unidimensional construct.
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32 The PSI was 0.64. Cronbach's alpha was 0.49. There was no DIF by age or gender, and only item
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34 36 revealed DIF by country. The Norwegians and the Danes revealed a higher level of unmet needs
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36 regarding "Help preparing for the worst" (item 36) than expected relative to their overall level of
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38 emotional needs. The location of persons was 0.03 (SD 1.68), indicating that this subscale targeted
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40 the level of the caregivers' emotional needs well, but with too few scoring options to cover the
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42 spectrum of emotional needs (Figure 2).
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52 *Need for Instrumental Support*

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54 The Need for Instrumental Support subscale (6 items) did not fit the Rasch model ($\chi^2 = 47.08$,
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56 $p = 0.003$). Item 20 and item 21 showed misfit to the Rasch model with fit residuals outside ± 2.5 .
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4 After removing these two items, the remaining four items fit the Rasch model (Table 4). The
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6 unidimensionality was also evaluated by the estimates of the most different items according to the
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8 PCA, which revealed that none of the t-tests were below 5%, indicating fit to one single underlying
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10 unidimensional construct. The PSI was 0.58. Cronbach's alpha was 0.30. The estimates of the most
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12 different items according to the PCA revealed no significant differences, supporting fit to the Rasch
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14 model. All items were invariant to age and gender, whereas items 22 and 23 revealed DIF by
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16 country (Table 3). The Colombians differed by having a higher level of unmet needs regarding rest
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18 and sleep (item 22) than expected related to their overall need for support in this subscale. The
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20 Norwegians reported a higher level of unmet needs regarding breaks from responsibilities (item 23),
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22 relative to their general need for instrumental support, than the participants in the other countries.
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24 The location of persons was -0.32, SD 1.53, indicating that the caregivers had a higher level of met
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26 needs than the subscale target, and again, the scoring distribution was narrower than the needs
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28 distribution of the persons included (Figure 3).
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36 *Need for Professional Support*

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38 The Need for Professional Support subscale (5 items) did fit the Rasch model (Table 4). The
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40 unidimensionality was also evaluated by the estimates of the most different items according to the
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42 PCA, which revealed that none of the t-tests were below 5%, indicating fit to one single underlying
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44 unidimensional construct. The PSI was 0.55. Cronbach's alpha was 0.29. The estimates of the most
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46 different items according to the PCA revealed no significant differences, supporting fit to the Rasch
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48 model. All items were invariant to age and gender, but only item 14 was invariant to country. The
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50 Norwegians reported the highest level of unmet needs regarding advice for strange behavior,
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52 relative to the general level of professional support needs, with the Mexicans reporting the lowest
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54 level of unmet needs in this item (item 15). The Norwegians had clearly lower levels of unmet
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4 needs regarding how much the patients should do for themselves (item 17) relative what was
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6 expected from their overall unmet needs. Regarding resources to the patients, Mexico had a higher
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8 level of unmet needs (item 18) than expected. Additionally, the Norwegians had a higher level of
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10 unmet needs than expected, and Denmark had lower levels than expected, regarding resources for
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12 the caregivers themselves (item 19).

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15 The location of persons was 0.15, SD 1.27, indicating a rather good target with a slightly higher
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17 level of unmet needs by caregivers than by items, and there was a rather narrow distribution of
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19 scoring options (Figure 4).

20 21 22 23 24 25 *Need for Community Support Network*

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27 The Need for a Community Support Network subscale (5 items) did not fit the Rasch model (χ^2
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29 =37.64, $p<0.01$).

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31 Item 29 had a high negative residual correlation indicating misfit, and after removing this item, fit
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33 to the Rasch model was obtained (Table 4). The unidimensionality was also evaluated by the
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35 estimates of the most different items according to the PCA, which revealed that none of the t-tests
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37 were below 5%, indicating fit to one single underlying unidimensional construct. The PSI was 0.36.
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39 Cronbach's alpha was 0.34. The estimates of the most different items according to the PCA
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41 revealed no significant differences, supporting fit to the Rasch model. All items were invariant to
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43 age and gender. Item 30 revealed DIF by country with the Mexicans clearly reported the lowest
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45 level of unmet needs regarding "To have the patient's employer, coworkers or teacher understand
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47 his/her problems" relative to the expected level given the overall needs of community support. The
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49 location of persons was 0.14, SD 1.07, indicating a rather good target with a slightly higher level of
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51 unmet needs by caregivers than by items, again, with a rather narrow range of scoring options
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57 (Figure 5).

Need for Involvement with Care

The Need for Involvement with Care subscale items (3 items) all fit a unidimensional construct, therefore all items in the subscale were retained. T-tests for unidimensionality could not be performed with three items. Additionally, regarding The Need for Involvement of Care, three items were insufficient for an acceptable power of the fit analysis. All items were invariant for age, whereas females reported a larger level of unmet needs regarding being ‘told daily what was being done with the patient’ (item 2). This item also varied across countries, with Mexicans having the highest degree of met needs. Item 3, regarding “being able to give daily opinions regarding the patient”, also showed DIF by country, with the Colombians having the highest levels of met needs relative to the overall need for involvement in care.

Discussion

The FNQ-R overall scale did not fit the Rasch model with an acceptable number of items retained, which supports previous work indicating several underlying dimensions of needs (6). However, five of the previous six subscales representing the caregiver’s needs for health information, emotional support, professional support and a community support network revealed fit to the Rasch model after some modification of the included items (6). The sixth subscale, representing need for involvement in care, comprises only three items and showed the lowest Cronbach’s alpha in the previous conventional factor analysis approach (6). It was not possible to fit this subscale to the Rasch model due to the low number of items and scoring options. It is worth noting that all three items in this subscale revealed fit to an overall five-item solution of the FNQ-R, indicating consistency with the needs concept for these items. In the future, additional relevant items or expansion of the scoring options may provide a basis for establishing a valid subscale regarding

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4 involvement in care, which may be of major importance, particularly in the later phases after brain
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6 injury (31).
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11 The fit to the Rasch model indicated unidimensional underlying constructs for each of the other five
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13 subscales after removing the misfitting items. This unidimensionality was verified by the low level
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15 of statistically significant estimates for subsets of items within each subscale (29). This is in line
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17 with the high level of internal consistency in the subscales that was previously identified (6). It is
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19 worth noting that the previous analysis was based on the perceived importance of each item,
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21 whereas the present analyses were based on the met/unmet needs of the items. Furthermore, the
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23 present analysis was based on log transformation of the ordinal scoring options into interval scaling
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25 according to the recommendations for the statistical approach (32). Hence, the present results
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27 underscore the FNQ-R as a valid and robust measurement of the dimensions of family needs after
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29 TBI but do not support an overall sum score for the FNQ-R. The FNQ-R was developed to measure
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31 family members' perceived needs after brain injuries. The dominant participants in the present
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33 study were **family members** of persons with TBI, **and only a few patients had severe brain injury**
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35 **caused by nontraumatic causes**. However, previous studies do indicate that caregivers' needs are
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37 more closely related to the impairment level of the person in care than the underlying diagnosis
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39 (33). **The level of caregiving among the participants may have varied largely according to the needs**
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41 **of the patients, living situation and the professional support as well as cultural and health system**
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43 **differences**.
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50 The response options (met, partly met and unmet needs) rendered a relatively narrow range of
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52 scoring options. However, for nine of the items, only two valid scoring options were documented,
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54 and partly met and unmet needs had to be combined for these items. The choice of combining partly
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56 met and unmet needs was based on the distribution of these options showing the largest degree of
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4 overlap for the majority of items, and a universal solution for rescoring all items was sought.
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6 However, from a service perspective, one may argue for collapsing unmet and partly met needs due
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8 to both representing a need for additional care. This choice was not assumed to influence the results
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10 of the present analysis but could be important when the scales are applied to identify needs for
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12 further services in clinical practice. However, although the items of the different subscales targeted
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14 the present participants' needs rather well, the scaling of the subscales was narrow, rendering both
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16 floor and ceiling challenges of the measurements (34). It is worth noting that Kreutzer et al. (13)
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18 applied a 10-point scoring option for assessing needs in their intervention study. This scaling has
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20 not been validated in terms of reliability, discriminative validity or responsiveness. However, given
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22 the results of the present study, further development of the scoring options of the FNQ-R is highly
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24 warranted in order to use the scale in prospective and interventional studies. **The low PSI may be**
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26 **related to the scoring options but also to the low number of items included in each of the subscales.**
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28 **Cronbach's alpha, however, was calculated without imputation of missing values in the present**
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30 **study, and thus underestimated the internal consistency of the subscales. Hence, expanding or**
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32 **deleting items and collapsing subscales may also be a solution in the future development of the**
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34 **FNQ-R.**
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43 The FNQ-R was invariant across age and gender, except for women having a higher level of unmet
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45 need for "To be told daily what is being done with or for the patient" than men relative to their
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47 general level of unmet needs. However, the DIF across countries revealed in more than half of the
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49 items represents a large challenge for cross-cultural application and comparison. First, the DIF
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51 revealed in many of the items may have been a cause of their misfit to the Rasch model (35). We
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53 did not have a sufficient number of persons from each country to split items by country and
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55 reevaluate fit to the Rasch model. Furthermore, the specific country differences varied from item to
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4 item and involved many of the countries. Hence, simple mathematical solutions would be difficult
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6 to find. The FNQ-R has been used extensively in research on families after brain injury (8, 9), and
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8 cross-cultural validity is needed from a statistical point of view.
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11 Further studies are warranted to untangle the causes of the country differences and explore more
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13 robust wording or content of the items to render them more culturally invariant. Differences in the
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15 patients' living situation and support could also influence the responses and interact with country
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17 differences. Better information of these factors should be focused in further studies. On the other
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19 hand, focusing too much on cultural invariance may cause removal of highly relevant needs items
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21 within specific countries or populations. With the development of web-based questionnaires,
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23 common items with additional country-specific items may be a feasible solution.
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26 27 *Conclusion*

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29 The present results clearly support the FNQ-R as a valid tool for measuring the Need for Health
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31 Information, Need for Emotional Support, Need for Instrumental Support, Need for Professional
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33 Support and Need for Community Support Network subscales. Expansion of items in the
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35 Involvement in Care subscale is recommended. The present study does not support the use of an
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37 overall sum score for FNQ-R, and caution with cross-cultural comparison is advised due to the
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39 variance across countries in several of the items.
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42 43 **Funding**

44
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46
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48
49 Mexican and Spanish investigators had no external financial support.
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51

52 53 **Disclosure**

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55 We have nothing to disclose.

56 57 **Biographical note**

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4 Cecilie Røe is an MD and the head of the Dept of Physical Medicine and Rehabilitation at Oslo
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52 **References**

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55 1. Wilson L, Stewart W, Dams-O'Connor K, Diaz-Arrastia R, Horton L, Menon DK, et al. The
56 chronic and evolving neurological consequences of traumatic brain injury. *Lancet Neurol.* 2017;16(10):813-
57 25. doi: S1474-4422(17)30279-X [pii];10.1016/S1474-4422(17)30279-X [doi].
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2. Ponsford J, Draper K, Schonberger M. Functional outcome 10 years after traumatic brain injury: its relationship with demographic, injury severity, and cognitive and emotional status. *J Int Neuropsychol Soc.* 2008;14(2):233-42.
3. Andelic N, Sjøberg HL, Berntsen SA, Sigurdardottir S, Røe C. Self-perceived health care needs and delivery of health care services 5 years after moderate-to-severe traumatic brain injury. *PM&R.* 2014;6(11):1013-21. doi: <http://dx.doi.org/10.1016/j.pmrj.2014.05.005>.
4. Kreutzer JW, P. *Community Integration Following Traumatic Brain Injuries.* Baltimore: Brookes; 1990.
5. Kreutzer J, Bergquist S. Family needs after brain injury. A quantitative analysis. *J Head Trauma Rehabil.* 1994;9(3):104-15.
6. Serio CD, Kreutzer JS, Witol AD. Family needs after traumatic brain injury: a factor analytic study of the Family Needs Questionnaire. *Brain Inj.* 1997;11(1):1-9.
7. Kreutzer JS, Marwitz JH, Klyce DW, Wilder Schaaf KP, Sima AP, Welch AM, et al. Family Needs on an Inpatient Brain Injury Rehabilitation Unit: A Quantitative Assessment. *J Head Trauma Rehabil.* 2018;33(4):228-36. doi: 10.1097/HTR.0000000000000390. PubMed PMID: 29601345.
8. Witol AD, Sander AM, Kreutzer JS. A longitudinal analysis of family needs following traumatic brain injury. *NeuroRehabilitation.* 1996;7(3):175-87. doi: 10.3233/NRE-1996-7303. PubMed PMID: 24525887.
9. Kolakowsky-Hayner SA, Miner KD, Kreutzer JS. Long-term life quality and family needs after traumatic brain injury. *J Head Trauma Rehabil.* 2001;16(4):374-85.
10. Moules S, Chandler BJ. A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain injury.* 1999;13(12):983-93. PubMed PMID: 10628503.
11. Anke A, Roe C, Sigurdardottir S, Norup A, Soberg HL, Arango-Lasprilla JC, et al. Family needs at one and two years after severe traumatic brain injury: a prospective study of changes and predictors. *Brain injury.* 2020;34(1):89-97. Epub 2019/10/28. doi: 10.1080/02699052.2019.1682191. PubMed PMID: 31647690.
12. Stebbins P, Leung P. Changing family needs after brain injury. *J Rehabil.* 1998;64(4):15-22. PubMed PMID: WOS:000077123300004.
13. Kreutzer JS, Marwitz JH, Sima AP, Godwin EE. Efficacy of the Brain Injury Family Intervention: Impact on Family Members. *J Head Trauma Rehabil.* 2015;30(4):249-60. doi: 10.1097/HTR.0000000000000144. PubMed PMID: 26147315.
14. Niemeier JP, Kreutzer JS, Marwitz JH, Sima AP. A Randomized Controlled Pilot Study of a Manualized Intervention for Caregivers of Patients With Traumatic Brain Injury in Inpatient Rehabilitation. *Arch Phys Med Rehabil.* 2019;100(4S):S65-S75. doi: 10.1016/j.apmr.2018.07.422. PubMed PMID: 30075147.
15. Terwee CB, Mokkink LB, Knol DL, Ostelo RW, Bouter LM, de Vet HC. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation.* 2012;21(4):651-7. doi: 10.1007/s11136-011-9960-1. PubMed PMID: 21732199; PubMed Central PMCID: PMC3323819.
16. Lindeboom R, Vermeulen M, Holman R, De Haan RJ. Activities of daily living instruments: optimizing scales for neurologic assessments. *Neurology.* 2003;60(5):738-42. doi: 10.1212/01.wnl.0000044402.16315.fc. PubMed PMID: 12630419.
17. Nakken N, Janssen DJ, van VM, de Vries GJ, Clappers-Gielen GA, Michels AJ, et al. Gender differences in partners of patients with COPD and their perceptions about the patients. *Int J Chron Obstruct Pulmon Dis.* 2017;12:95-104. doi: 10.2147/COPD.S118871 [doi];copd-12-095 [pii].
18. Norup A, Perrin PB, Cuberos-Urbano G, Anke A, Andelic N, Doyle ST, et al. Family needs after brain injury: A cross cultural study. *Neurorehabilitation.* 2015;36(2):203-14. doi: NRE1208 [pii];10.3233/NRE-151208 [doi].

19. Arango-Lasprilla JC, Quijano MC, Aponte M, Cuervo MT, Nicholls E, Rogers HL, et al. Family needs in caregivers of individuals with traumatic brain injury from Colombia, South America. *Brain injury*. 2010;24(7-8):1017-26. doi: 10.3109/02699052.2010.490516. PubMed PMID: 20545455.
20. Doser K, Norup A. Family needs in the chronic phase after severe brain injury in Denmark. *Brain Inj*. 2014;28(10):1230-7. doi: 10.3109/02699052.2014.915985 [doi].
21. Manskow US, Arntzen C, Damsgård E, Braine M, Sigurdardottir S, Andelic N, et al. Family members' experience with in-hospital health care after severe traumatic brain injury: a national multicentre study. *BMC Health Services Research*. 2018;8(951):10. doi: <http://dx.doi.org/10.1186/s12913-018-3773-7>.
22. Kreutzer JS, Rapport LJ, Marwitz JH, Harrison-Felix C, Hart T, Glenn M, et al. Caregivers' well-being after traumatic brain injury: a multicenter prospective investigation. *ArchPhysMedRehabil*. 2009;90(6):939-46.
23. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol*. 1993;46(12):1417-32.
24. Rasch G. Probabilistic models for some intelligence and attainment tests. Chicago, USA: University of Chicago Press; 1960 1960.
25. Masters G. A Rasch model for partial credit scoring. *Psychometrika*. 1982;47:149-74.
26. Wright BD, Mok M. Rasch models overview. *JApplMeas*. 2000;1(1):83-106.
27. Andrich D. Rasch models for measurements. *Quantitative Application in Social Sciences*. London: Sage; 1988.
28. Angoff WH. Perspectives on differential item functioning methodology. In: . HPW, Weiner H, editors. *Differential item functioning*. Mahwah, New Jersey, USA: Lawrence Erlbaum; 1993. p. 3-23.
29. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis Rheum*. 2007;57(8):1358-62. Epub 2007/12/01. doi: 10.1002/art.23108. PubMed PMID: 18050173.
30. Bland JM, Altman DG. Multiple significance tests: the Bonferroni method. *Br Med J*. 1995;310:170.
31. Fisher A, Bellon M, Lawn S, Lennon S, Sohlberg M. Family-directed approach to brain injury (FAB) model: a preliminary framework to guide family-directed intervention for individuals with brain injury. *Disabil Rehabil*. 2019;41(7):854-60. doi: 10.1080/09638288.2017.1407966. PubMed PMID: 29171308.
32. Grimby G, Tennant A, Tesio L. The use of raw scores from ordinal scales: time to end malpractice? *J Rehabil Med*. 2012;44(2):97-8. doi: 10.2340/16501977-0938. PubMed PMID: 22334345.
33. Tramonti F, Bonfiglio L, Bongioanni P, Belviso C, Fanciullacci C, Rossi B, et al. Caregiver burden and family functioning in different neurological diseases. *Psychology, health & medicine*. 2019;24(1):27-34. doi: 10.1080/13548506.2018.1510131. PubMed PMID: 30141703.
34. McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are available health status surveys adequate? *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 1995;4(4):293-307. PubMed PMID: 7550178.
35. Hagquist C, Andrich D. Recent advances in analysis of differential item functioning in health research using the Rasch model. *Health Qual Life Outcomes*. 2017;15(1):181. doi: 10.1186/s12955-017-0755-0. PubMed PMID: 28927468; PubMed Central PMCID: PMC5606090.

Figure legends (Five figures)

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4 **Fig 1.** Distribution of the scores for the six items of the Need for Health Information subscale of *the*
5 Family Needs Questionnaire-Revised with fit to a unidimensional construct and the scores of family
6 members of patients with traumatic brain injury on the same logit scale. N=307, Persons location
7 mean 0.46, SD 1.63.
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15 **Fig 2.** Distribution of the scores for the six items of the Need for Emotional Support subscale of the
16 Family Needs Questionnaire-Revised with fit to a unidimensional construct and the scores for the
17 family member of patients with traumatic brain injury on the same logit scale. N=305, Persons
18 location mean 0.03, SD 1.68.
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30 **Fig 3.** Distribution of the scores for the four items of the Need for Instrumental Support subscale of
31 the Family Needs Questionnaire Revised with fit to a unidimensional construct and the scores for
32 the family member of patients with traumatic brain injury on the same logit scale. N=305, Persons
33 location mean -0.32, SD 1.53.
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44 **Fig 4.** Distribution of the scores for the 5 items of the Need for Professional Support subscale of the
45 Family Needs Questionnaire Revised with fit to a unidimensional construct and the scores for the
46 family member of patients with traumatic brain injury on the same logit scale. N=303, Persons
47 location mean 0.15, SD 1.27.
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Fig 5. Distribution of the scores for the four items of the Need for Community Support Network subscale of the Family Needs Questionnaire Revised with fit to a unidimensional construct and the scores for the family member of patients with traumatic brain injury on the same logit scale. N=306, Persons location mean 0.14, SD 1.07.

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