

CROSS-CULTURAL ADAPTATION OF THE INSTRUMENT "FAMILY NEEDS QUESTIONNAIRE"

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Hora EC, Sousa RMC. cross-cultural adaptation of the instrument "Family Needs Questionnaire". Rev Latino-am Enfermagem 2009 julho-agosto; 17(4):541-7.

This is a quantitative methodological development study on the cross-cultural adaptation of the "Family Needs Questionnaire" (FNQ), which is a structured instrument developed in the United States to measure the perceived needs of family members after the Traumatic Brain Injury (TBI) of a relative. This instrument aims to identify important needs presented by family members, whether met or not. The FNQ translation and adaptation followed a particular method, which permitted to achieve semantic, idiomatic, cultural and conceptual equivalence of the instrument version labeled in Portuguese as "Questionário de Necessidades da Família". The results of the questionnaire application to 161 family members showed that the instrument content is valid to measure the needs of families of patients with TBI in the Brazilian context.

DESCRIPTORS: validation studies; translating; brain injuries; family; family nursing

ADAPTACIÓN TRANSCULTURAL DEL INSTRUMENTO FAMILY NEEDS QUESTIONNAIRE

Se trata de estudio cuantitativo de desarrollo metodológico sobre la adaptación transcultural del Family Needs Questionnaire (FNQ), instrumento estructurado, desarrollado en los Estados Unidos, para medir las necesidades percibidas por los miembros de la familia, después del trauma craneo encefálico (TCE) de un familiar. El propósito de ese instrumento es identificar necesidades atendidas y no atendidas importantes para los familiares. La traducción y adaptación del FNQ siguieron una metodología propia que permitió alcanzar equivalencia semántica, idiomática, cultural y conceptual del instrumento traducido, denominado, en portugués, Cuestionario de Necesidades de la Familia. Los resultados de la aplicación del cuestionario en 161 familiares mostraron que el contenido del instrumento es válido para medir, en nuestro medio, las necesidades de los familiares que tiene personas con TCE.

DESCRIPTORES: estudios de validación; traducción (proceso); traumatismos encefálicos; familia, enfermería familiar

ADAPTAÇÃO TRANSCULTURAL DO INSTRUMENTO FAMILY NEEDS QUESTIONNAIRE

Trata-se de estudo quantitativo de desenvolvimento metodológico sobre a adaptação transcultural do Family Needs Questionnaire (FNQ), instrumento estruturado, desenvolvido nos Estados Unidos, para medir as necessidades percebidas pelos membros da família, após o trauma cranioencefálico (TCE) de um familiar. O propósito desse instrumento é identificar necessidades atendidas e não atendidas importantes para os familiares. A tradução e adaptação do FNQ seguiram metodologia própria que permitiu alcançar equivalência semântica, idiomática, cultural e conceitual do instrumento traduzido, denominado, em português, Questionário de Necessidades da Família. Os resultados da aplicação do questionário em 161 familiares mostraram que o conteúdo do instrumento é válido para medir, em nosso meio, as necessidades dos familiares que têm pessoas com TCE.

DESCRIPTORES: estudos de validação; tradução (processo); traumatismos encefálicos; família, enfermagem familiar

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INTRODUCTION

In the group of lesions that occur due to external causes, traumatic brain injury (TBI) is one of the most frequent and is mainly caused by accidents and violence. It is a public health problem of great importance that has a strong social impact on the population's morbidity and mortality. Patients who survive TBI might present deficiencies and incapacities that can be temporary or permanent and interfere in individuals' capacity to perform tasks⁽¹⁾.

For many years, literature on TBI has focused on the victims of trauma, although it has recently attempted to report the TBI impact on the family system as well⁽²⁾. The impact TBI causes in the family leads to countless consequences and the following are highlighted: stress and sorrow⁽³⁾, change in family roles⁽⁴⁾, guilt and anger⁽⁵⁾, difficulties in the sexual and marital relationship⁽⁶⁾, depression⁽⁷⁾, anxiety⁽⁸⁾, psychosomatic disorders⁽⁹⁾ and reduced quality of life⁽¹⁰⁾.

Families experience several needs in the initial period of crisis following TBI, however, as TBI has long-term effects, it is also important to evaluate these needs after the initial period of crisis⁽¹⁰⁾.

In view of the urgent need to evaluate these needs in clinical practice, after a comprehensive search in the literature for instruments to measure families' needs, we decided to make a cross-cultural adaptation of the Family Needs Questionnaire (FNQ), which is a reliable and valid instrument used for the U.S. culture that identifies the needs of families of people with TBI and takes into account their specificities.

The FNQ was developed in Virginia, U.S.⁽¹¹⁾ in an attempt to standardize the measures of needs of TBI victims' families. Its development was based on an extensive literature review and interviews with families, aiming to represent the range of needs of family members after a TBI of a relative.

The instrument indicates several psychosocial and educational needs, visible in the acute and post acute phase of TBI. Clinically, the answers obtained from family members can be used for evaluation and intervention. The FNQ has therefore potential to improve the understanding of family members' needs⁽¹²⁾.

The FNQ is a 40-item questionnaire with six subscales: health information, emotional support, instrumental support, professional support, community

support network and involvement with care. It is self-applied and composed of two parts that comprise two independent evaluations. Part I measures the importance of needs through a Likert scale that varies from 1 (not important) to 4 (very important) and Part II measures to what extent such needs are met. Family members can also define needs as non-applicable. At the end, the FNQ presents an open question that allows family members to describe needs not included in the instrument items⁽¹³⁾.

The result of the first part is obtained by adding up items considered "important" (3) and "very important" (4) only, whereas the results of the second part are obtained by the sum of items families considered met, partially met and not met, which were scored in the previous part. The final result is achieved by the division of the two previous results, aiming to obtain a percentage of total needs considered "important" and "very important" and which need to be met so as to provide support to program interventions.

In view of the problems faced by families of TBI victims and the lack of an adequate instrument to measure the needs of Brazilian families in the post acute phase of TBI, we aimed to perform a cross-cultural adaptation of the FNQ (translation to Portuguese language and adaptation for the Brazilian culture) and validate the content of its adapted version, so that professionals would have an instrument to better know the needs of families and help them to adapt to the new situation of having a relative with TBI.

CASUISTIC AND METHOD

This is a quantitative study with methodological development. It was developed in two phases: the first included experts in the English language and nurse experts in psychometrics, neurotrauma and family. In the second phase, initially, a group of 20 family members of TBI victims was interviewed, followed by another 161 family members. The 20 family members analyzed the understanding and clarity of the instrument items and the second group answered the FNQ. The 161 participants were relatives of 71 patients with TBI who received care either in a referral hospital for trauma or in a medical specialty center that is a referral institution for neurosurgery outpatients, both located in Aracaju, SE, Brazil.

The inclusion criteria for family members were: being 18 years or older, minimum education of five complete years, and according to the FNQ manual: participate in care for patients who had suffered TBI at least six months before and who were older than 12 years at the time of the interview, which is the period of stabilization in the recovery process for this kind of lesion⁽¹⁾.

The study was approved by the Research Ethics Committee and family members were included in the study only after their consent. The authorization

for the FNQ cross-cultural adaptation was obtained from the National Resource Center for Traumatic Brain Injury, an organization at the Virginia Commonwealth University, Richmond, VA, U.S., which has the copyright of the instrument.

Procedures: the cross-cultural adaptation was a process that comprised five stages: evaluation of semantic, idiomatic, cultural and conceptual equivalence between the original and translated versions in order to validate the instrument content⁽¹⁴⁾.

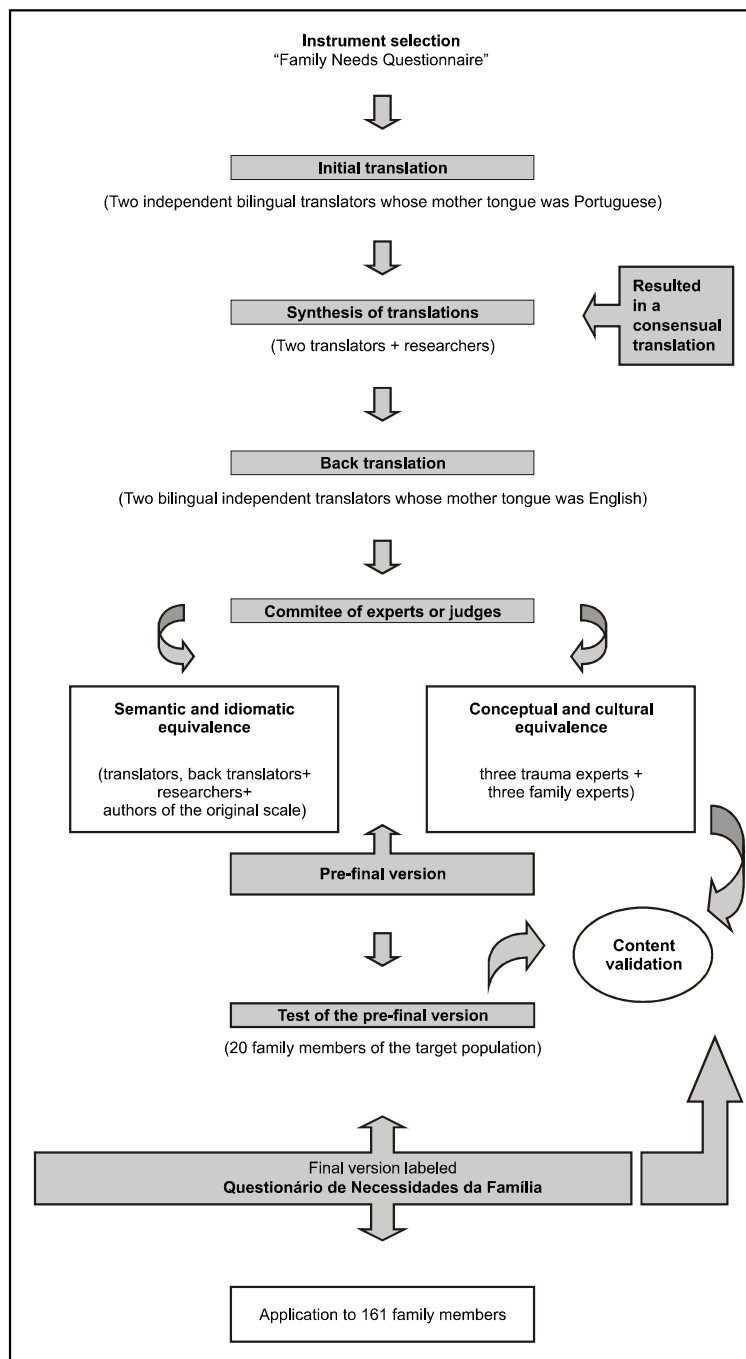


Figure 1 – Summary of the cross-cultural adaptation and content validation of Family Needs Questionnaire. Sergipe, Brazil 2005

Stage I - Initial translation: first, two independent bilingual translators, whose mother tongue was Portuguese, translated the FNQ from its original version in English to Portuguese, so that discrepancies would be compared and identified. The two translators had different backgrounds, one was a nursing professor with a doctoral degree and the other had a bachelor's degree in translation and interpretation. The first translator was informed about the questionnaire's concepts that were to be examined and translated so as to provide a more clinical perspective. The other translator, considered "naïve", received no information and had no professional training on the subject under study, so his translation would reflect language commonly used by the population.

Stage II - Synthesis of translations: a synthesis of the two translations was performed, with the participation of the two initial translators and the two researchers who were the mediators in the discussion on translation differences, which resulted in a consensual translation.

Stage III - Back-translation: this version was back translated to the English language. Two independent bilingual translators whose mother tongue was English made the two back-translations. This process aimed to validate the instrument's content, that is, to verify whether the translated version precisely reflected the content of the original version and identify any inconsistencies or conceptual errors.

Stage IV - Committees of experts or judges: two committees were formed so as to achieve semantic, idiomatic, cultural and conceptual equivalence between the original instrument and the translated version. To evaluate semantic and idiomatic equivalence, all those responsible for the translations and back-translations were involved in the process, in addition to researchers and authors of the original instrument. Another committee of six judges was formed for conceptual and cultural equivalence: three experts in trauma and another three in family. An evaluation form was developed for this assessment. The percentage of agreement between judges concerning cultural and conceptual evaluations was calculated for each of the 40 items of the FNQ translated version through the ratio between the number of indications of equivalence of one item in relation to the total number of judges⁽¹⁵⁾. Items that obtained at least 80% of agreement between judges were accepted as

equivalent. Additionally, the Index of Content Validity (ICV), proposed in 1991⁽¹⁵⁾, was calculated for each pair of judges. This index is defined as the ratio between the items considered equivalent by two judges and the total number of scale items.

Stage V - Test of the Pre-final version: the final phase of the adaptation process was the pre-test. This test of the new questionnaire used the pre-final version, consolidated by the committees of experts, to evaluate items understanding and clarity. Twenty individuals from the target population completed the questionnaire and were interviewed so as to investigate the meaning of each item and answer choices. The aim of checking these two aspects was to ensure that, when the adapted version was applied, it would maintain its equivalence. The instrument's final version was obtained after the analysis of the pre-test results.

Content validity: although the process of cross-cultural adaptation provides indications of the instrument's content validity, an additional test was used through the application of the questionnaire to 161 families of TBI victims. To evaluate whether the instrument content was adequate, we analyzed answers related to the importance of the needs described in the FNQ and answers to an open question that allowed family members to describe needs not included in the instrument items. In this phase, the Average Proportional Index of Needs was computed as indicated by the FNQ⁽¹²⁾ to measure the average importance of needs. The percentage of importance for each family member was computed by dividing the total needs, considered "important" or "very important", by the total number of items. Using this procedure, another percentage was computed by dividing the total number of needs considered "not important" by the total number of items. At the end of this process, the average and standard deviation of the percentages of all family members were calculated.

RESULTS

After the first three stages of the FNQ cross-cultural adaptation process, which comprised translation, synthesis of translations and back-translations, an evaluation of semantic and idiomatic equivalence between the original and translated

version was performed during a meeting with the participation of all those involved in the previous stages. This evaluation resulted in the translated instrument, which was submitted to the committee of six experts in the areas of trauma and family, who evaluated the instrument's cultural and conceptual equivalence. The results of this analysis showed agreement ratios among judges of 100% for 30 items, while only item 11 did not reach the minimum agreement level established for this study (80%). For this item, the indexes were 67% for conceptual and 50% for cultural equivalence.

At the end of this phase, item 11 was changed according to the judges' suggestion and the translation "having complete information on the medical care of traumatic lesions (i.e. medication, injections, or surgery)" was altered to "having complete information on the treatment of traumatic lesions (i.e. medication, injection or surgery)"

The Content validity index (CVI), computed for each pair of judges, is presented in Tables 1 and 2. We observe in the tables that the lowest CVI was 0.83, corresponding to 83% of agreement between the answers of two judges, which indicates the instrument's content validity.

Table 1 – Content Validity Index in the evaluation of cultural equivalence of the items of the Family Needs Questionnaire - translated version. Sergipe, 2005

Cultural	Judge 1	Judge 2	Judge 3	Judge 4	Judge 5	Judge 6
Judge 1	1.00	0.85	0.95	0.93	0.95	0.93
Judge 2		1.00	0.90	0.90	0.90	0.90
Judge 3			1.00	0.98	1.00	0.98
Judge 4				1.00	0.98	0.98
Judge 5					1.00	0.98
Judge 6						1.00

Table 2 – Content Validity Index in the evaluation of conceptual equivalence of the items of the Family Needs Questionnaire - translated version. Sergipe, 2005

Conceptual	Judge 1	Judge 2	Judge 3	Judge 4	Judge 5	Judge 6
Judge 1	1.00	0.83	0.95	0.83	0.95	0.95
Judge 2		1.00	0.90	0.83	0.90	0.90
Judge 3			1.00	0.88	1.00	1.00
Judge 4				1.00	0.88	0.88
Judge 5					1.00	1.00
Judge 6						1.00

At the end of the forth stage, the committee of experts presented its pre-final version labeled *Questionário de Necessidades da Família*. This version was tested in families of the target population. The result indicated the need to include a specific column to list non-applicable items and mainly observe the item: "to have different professionals agree on the best way to help the patient" and "to be reassured that it is usual to have strong negative feelings about the patient". These two items were considered difficult to understand by three (15%) of the 20 participants, probably because they were not familiar with the multidisciplinary work involved in care to the victim and behavioral consequences after TBI, which generate negative feelings in family members.

The FNQ final content validation process was carried out with 161 family members, with an average age of 35.7 years (standard deviation of 14.8), most of whom were the main caregiver (75.2%), female (82.6%), catholic (73.3%), with incomplete primary school (42.2%), married or cohabitating (47.8%), with monthly income of one to two minimum wages (62.1%), mother or sister of TBI victims (56.5%).

The average and standard deviation of the Proportional Index of Needs of these family members are presented in Table 3. The average percentage of needs considered "important" and "very important" was very high (93.1%), opposed to the value of those considered "not important", with a low average percentage (3.5%).

Table 3 - Average (X) and standard deviation (SD) of the Proportional Index of Needs of family members. Sergipe, 2005

Evaluation of needs by family members	X ± SD
"Important or very important"	93.1 % ±10.3
"Not important"	3.5 % ± 6.5

The results of the open question included in the *Questionário de Necessidades da Família* about "other needs not included", answered by 17 (10.6%) family members, are described in Table 4. The needs were grouped under four labels according to the content presented and, despite their reduced number, they should be taken into account.

Table 4 – Needs not included in the *Questionário de Necessidades da Família* and presented by family members. Sergipe, 2005

I need...
that the patient is oriented and accompanied by the health team in the service
<i>To have a care service after hospital discharge</i>
<i>Medical follow-up</i>
<i>The patient is followed-up by the health team</i>
<i>I need an expert to frequently talk to the patient</i>
<i>Follow-up by a team</i>
<i>Medical and psychologist consultation</i>
<i>A physician to help him</i>
<i>Medical treatment</i>
<i>An anti-drugs treatment with a psychologist</i>
<i>Guidance for the patient, so he knows how to treat family members, especially children</i>
<i>I need the patient's understanding</i>
<i>Guidance for the patient</i>
Orientation about convulsive crises
<i>I need orientation about convulsive crises because people think it is transmissible and he also, sometimes, he forgets to take the medication</i>
Health policies and support from the community
<i>Awareness from the community - to respect the sick person</i>
<i>It is needed that people who suffer any kind of disease has more support from the government</i>
<i>I need medication for the patient, it's very expensive and it is hard for those who have financial difficulties</i>
Spiritual support
<i>I need spiritual support</i>

We observed in the answers of the 161 family members that ten items were appointed as “non-applicable”. Among them, more than one family member indicated the items: 1 “to be shown that the medical, educational or rehabilitation staff respect the patient’s needs or wishes” (4.5%), 5 “be assured that the best possible medical care is being given to the patient”(1.5%), 8 “to be shown that my opinions are used in planning the patient’s treatment, rehabilitation or education” (2.3%), 10 “to have different professionals agree on the best way to help the patient” (3.8%), 33 “to have the patient’s employer, co-workers or teachers understand his/her problems” (28.8%) and 36 “to be reassured that it is usual to have strong negative feelings about the patient” (5.3%)”.

DISCUSSION

During the FNQ⁽¹⁴⁾ cross-cultural translation and adaptation, the translated version labeled “*Questionário de Necessidades da Família*” showed semantic, idiomatic, cultural and conceptual equivalence after the experts’ evaluation, which provided face validity and content validity measures.

The questionnaire’s additional test of content validity, carried out through the application of the

instrument to 161 relatives of TBI victims, confirmed that the instrument is valid to measure the needs of families of patients with TBI in the Brazilian context.

In the application of this questionnaire, we observed a high average proportional index of need (93.1%) in relation to the items considered “important” or “very important”. Additionally, family members’ frequent evaluation of the needs described in the items as “important” and “very important” also supported the instrument’s content validity.

In a study performed with 119 American families, the FNQ also presented a high average proportional index of need for items considered “important” or “very important” (84%), while nine (23%) of the 40 items were considered “important” or “very important” by more than 95% of family members⁽¹²⁾.

Inversely, the average proportional index of needs considered “not important” was considerably low (3.5%), whereas only two items obtained percentages higher than 10%. These results are similar to those of a U.S. study that applied the FNQ⁽¹²⁾ and obtained a 7% index of needs considered “not important”. These authors⁽¹²⁾ affirm that the low average of “not important” items strengthens the questionnaire’s content validity even more.

The number of non-applicable needs was very low and only the item “having the employers’, co-workers’ or teachers’ understanding concerning the

patients' problems" obtained an expressive percentage (28.8%), which is justified due to the great number of patients on sick leave, away from work or school during the period of the questionnaire application.

The open question about needs "not included" in the questionnaire was very important to verify whether some need had not been considered for this culturally different sample. In the groups of needs, the answer "I need that the patient is oriented and is followed by a health team in the service" is related to needs already included in the items "to have a professional to turn to for advice or services when the patient needs help" and "to have enough resources for the patient (i.e. rehabilitation programs, physical therapy, counseling and job counseling)" of the questionnaire. Similarly, the group "having orientation about convulsive crises" can also be included under "to have complete information on the patient's physical problems (i.e. weakness, headache, dizziness, problems with vision or walking)" that is, all the suggested issues can be included to attend to specific needs.

It is important to highlight that, despite the growing number of studies focusing on the evaluation of family members' needs through instruments,

especially in Intensive Care Units⁽¹⁶⁾, no studies focusing on the evaluation of specific needs of families of patients with TBI was found in the Brazilian literature, although this is a very relevant public health problem in Brazil.

CONCLUSION

The FNQ Brazilian version, labeled *Questionário de Necessidades da Família*, showed proprieties that certified its quality through semantic, idiomatic, cultural and conceptual equivalence, providing face and content validity to evaluate the needs of families of TBI victims in the Brazilian context.

Considering the high level of importance that all items in the questionnaire obtained from family members and also the sample specificity (from a single region in Brazil), internal consistency or homogeneity and construct validity, through factor analysis, should be performed with larger and more diverse samples (other regional groups), taking into account a larger number of family members who are the main caregivers so as to confirm the results.

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