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Ethical Approval

The study was approved by the Institutional Review Board of the Catholic University of Rio Grande do Sul (72225317.2.0000.5336) and authorized by the original author of the EMPATHIC-30 (personal communication). All patients signed the informed consent form.

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ABSTRACT

Objective: To conduct the Brazilian translation, cross-cultural adaptation, validation and reliability testing of the EMPowerment of PArents in THe Intensive Care (EMPATHIC-30).

Design: Prospective study.

Setting: Pediatric intensive care unit (PICU) of a tertiary care teaching hospital.

Patients: Parents (n=141) completed the translated EMPATHIC-30 questionnaire 72 hours after their child's PICU discharge.

Interventions: None.

Measurements and Main Results: The translation and cultural adaptation were performed in accordance with the Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes Measures. Sentences were adapted according to the Brazilian syntax. Total content validity coefficient (CVC) was above the established average (> 0.8). Reliability was evaluated with the coefficients McDonald's omega and Cronbach's Alpha. The lowest Cronbach's alpha found was 0.47 (CI. 95%: 0.35; 0.59) in the organization domain, where the lowest response rate was also concentrated. The values of the other domains were: 0.64 (95% CI: 0.55, 0.73) for information, 0.77 (95% CI: 0.71, 0.83) for care and treatment, 0.72 (95% CI: 0.66, 0.78) for parent participation and 0.72 (95% CI: 0.65, 0.79) for professional attitudes. The total internal consistency independent of the domain was 0.90 (CI. 95%: 0.88, 0.92). With regard to McDonald's Omega, values were identified: 0.68 (95% CI: 0.49, 0.88) for information, 0.73 (95% CI: 0.61, 0.85) for care and treatment, 0.85 (95% CI: 0.47, 0.80) for parent participation, 0.85 (95% CI: 0.76, 0.93) and 0.72 (95% CI: 0, 58; 0.86) for professional attitudes.

Conclusion: EMPATHIC-30 has been translated and culturally adapted for the Brazilian population. Validation demonstrated an above average total CVC, confirming the instrument content validity. A sufficient reliability was observed in both analyzed coefficients. The results support the use of the Brazilian version of EMPATHIC-30 for the evaluation of parents' satisfaction of children admitted to the PICU.

Keywords: Patient satisfaction; Intensive care units; Pediatric; Reproducibility of results; Children; Patient reported outcomes measures.

INTRODUCTION

Patients satisfaction has gained increasing attention over the past 20 years since it may help identify gaps in hospital performance (1, 2). In this context, patients' family experience and satisfaction also play an important role (3), especially when considering pediatric patients in life threatening situations, as frequently seen in pediatric intensive care units (PICU). From the family perspective and patient-centered care, parents satisfaction about the care provided to their children represents a key quality performance indicator (2).

When well documented, patient satisfaction data can be used for benchmarking among hospitals and to measure the impact of it on hospital performance (4, 5). Although the need to understand patient and family satisfaction is well established in the literature, few validated tools are available in the literature to effectively measure the outcomes in PICU (3). Most of the evaluation questionnaires do not have validity, reliability or specificity for different hospitalization settings. To ensure reliable comparisons of satisfaction data in a hospital setting, clinicians must consider using similar validated instruments for benchmarking satisfaction outcomes measures (6).

In the Netherlands, due to the lack of validated instruments, the EMPowerment of PArents in THe Intensive Care 30 (EMPATHIC-30) questionnaire was developed to assess parental satisfaction in PICU (7). In Brazil, no validated questionnaires were found for this type of research and measuring parent experiences and satisfaction to improve clinical practice.

In this study, we performed the translation and cross-cultural adaptation of the EMPATHIC-30 questionnaire and assessed the validation and reliability of the questionnaire for use in Brazil. In addition, we evaluated the relationship among sociodemographic variables and the domains of the EMPATHIC-30 questionnaire.

METHODS

Study design

This study adopted an explorative psychometric design for the translation, cross-cultural adaptation and validation of the EMPATHIC-30 for the Brazilian context.

Setting and participants

The study was conducted at the PICU at a University Hospital of Southern Brazil, which is responsible for the private care of patients or those coming from the public health system, aged between 29 days and 18 years. The Brazilian Unified Health System (SUS) is a government-funded universal healthcare system that includes the public provision of family and specialist doctors and hospital services without any copayments or patient charges. The PICU is a 12-bedded unit with around 400 admissions per year. Data collection was performed between January and June 2018.

We included parents or legal representatives (n=141) over 18 years and over 24 hours of hospitalization of the child in the PICU. We excluded parents (or legal representatives) of children who died at the PICU, re-hospitalized children and participants who declared themselves illiterate.

Translation and cross-cultural adaptation

The translation and cultural adaptation of EMPATHIC-30 were performed in accordance with the protocol established by the International Society for Pharmacoeconomic Research (ISPOR) (8). Figure 1 demonstrates the steps we followed.

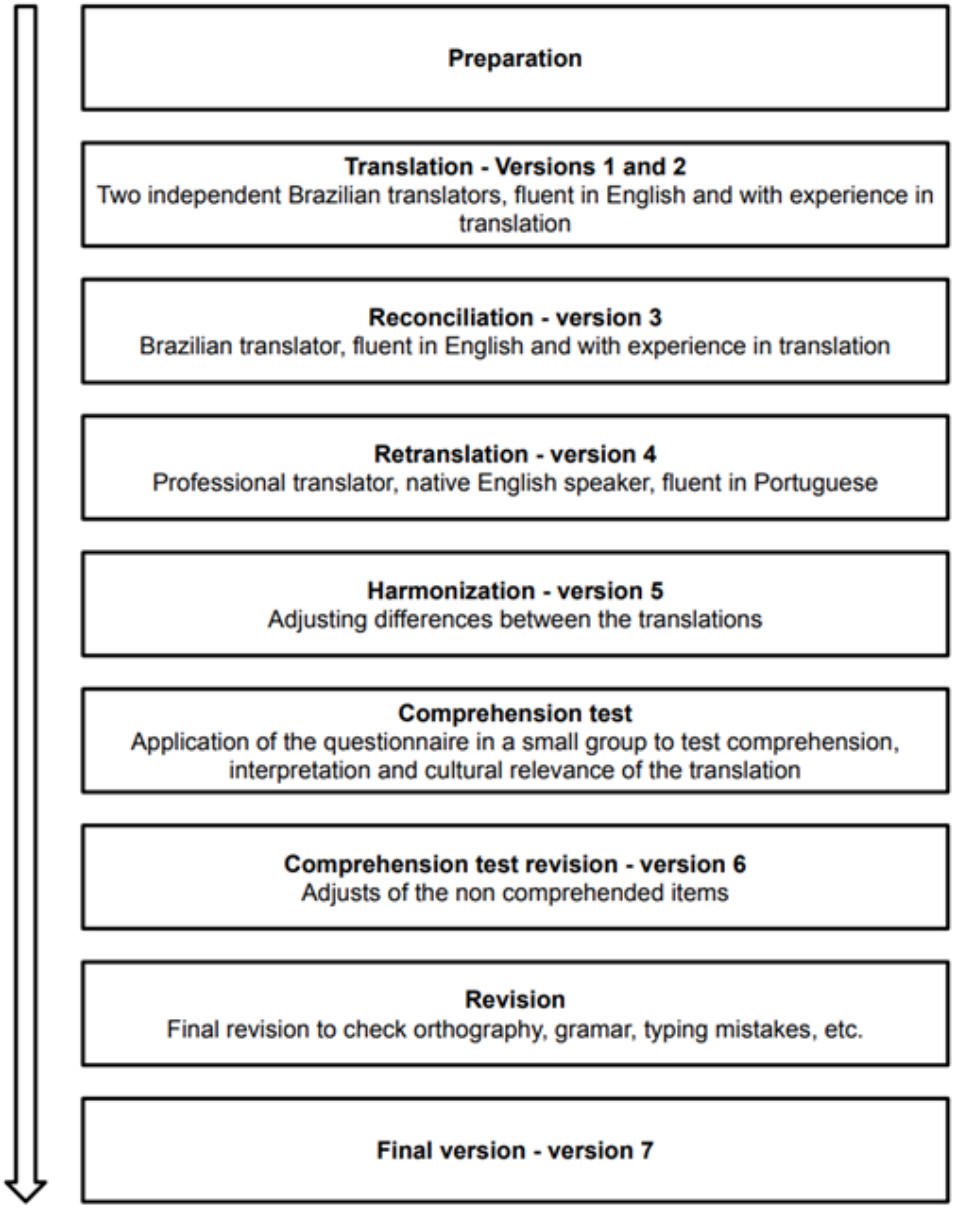

Figure 1: Translation and cross-cultural adaptation methodology in accordance with the protocol established by the International Society for Pharmacoeconomic Research (ISPOR).

In the preparation phase, we contacted the author of the original instrument to request his authorization for the translation, cultural adaptation and validation of EMPATHIC-30 in Brazil. We also recruited the translators and provided explanations of instrument concepts and the ISPOR methodology.

The translation consisted of the elaboration of two versions, each translated by independent translators, both Brazilians and fluent in English. In the reconciliation phase, the authors reviewed both versions and prepared a single questionnaire in Portuguese. The questions were also compared with the translation of the EMpowerment of PArent in The Intensive Care Neonatology (EMPATHIC-N) translated and validated in Brazil (9). The translation from Portuguese to English was performed by a native English speaker translator, fluent in Portuguese, who was unaware of the original version.

After this process, a comprehension test was performed with the patients' parents (n= 14). The questionnaire was administered within 72 hours after the PICU discharge, during the hospitalization in the pediatric inpatient unit. This time was determined to cover patients discharged over the weekend. The questionnaire was applied by two researchers, after the signature of the Informed Consent Form by the parents, who were consecutively selected. In addition to the instrument, participants also answered a sociodemographic questionnaire.

In the test review stage, the sentences, expressions and words not understood by the participants were analyzed and the necessary modifications were made to improve the instrument. After the revision of the spelling and syntax of the text was performed, the EMPATHIC-30 Brazil was considered to be final for further testing. (**Supplementary material 1**).

Content-related validity of the final version was performed by a panel of experts. Professionals working in the PICU were invited to participate in the evaluation (10). The selection was made by convenience. The researcher went to the unit once a day for two weeks to deliver and collect the questionnaires.

Experts evaluated the relevance of the questionnaire items on a Likert Scale from 1 (very irrelevant) to 5 (very relevant), in addition to a qualitative comment section for participants to provide feedback.

Data analysis

The final version of the translated EMPATHIC-30 questionnaire was used and parents were invited to participate up to 72 hours after discharge from the PICU patient. After discharge from PICU, patients were transferred to the pediatric ward, approximately 1/3 of these patients continued to be attended by PICU's medical staff, as this is a routine procedure in the hospital where the study was conducted. This instrument is composed of 30 questions divided into five domains (information, care and treatment, organization, parental participation and attitude of professionals), which provide a comprehensive conceptualization of parental satisfaction. The answers option scale is a six-point scale, which ranges from 1 (certainly no) to 6 (certainly yes).

Categorical variables were described as absolute and relative frequency, while continuous variables were described as mean and standard deviation (SD) or median and interquartile range (IQR), according to the distribution of the variable.

The psychometric properties evaluated were content validity and reliability. Content-related validity was performed by a committee of experts. Experts evaluated the relevance of the questionnaire items on a Likert Scale from 01 (very irrelevant) to 05 (very relevant), in addition to a qualitative consideration. Mean and SD were calculated for all items. After that, the content validity coefficient (CVC) was calculated for each item and for the instrument as a whole, using the CVC criterion >0.80(11). The analysis was performed using Microsoft Office Excel software.

To assess the internal consistency, the domains were calculated considering the complete cases of the domain questions and the number of missing cases per question

were described. The reliability of the translated questionnaire was evaluated with the coefficients McDonald's omega (11) and Cronbach's alpha (12) within each item, domain and in general. It was considered that a Cronbach's alpha and McDonald's omega values greater than 0.70 is assumed to be satisfactory.

The relationship between the domains of the scale and categorical sociodemographic variables was verified using the Kruskal-Wallis test or the Wilcoxon Mann-Whitney test. The analysis was performed in software R, version 3.5.3 and the level of significance was 5%.

Ethical considerations

The study was approved by the Institutional Review Board of the Catholic University of Rio Grande do Sul (72225317.2.0000.5336) and authorized by the original author of the EMPATHIC-30 (personal communication). All patients signed the informed consent form.

RESULTS

Translation and cross-cultural validation

In the translation stage (forward and backward translation), there were only a few differences between the two versions related to the use of distinct words in four items. The structure and sequence of the questions were maintained according to the original instrument as well as the domain titles. In the reconciliation phase, the most common words were used for the studied population. The tenses were kept, and the sequence of some sentences were reversed according to the Brazilian Portuguese syntax. Some sentences have already been modified at this stage, taking into consideration the comparison with the translation of EMPATHIC-N that has been validated in Brazil.

Supplementary material 2 demonstrates the modified words in the reconciliation phase (available only in Portuguese).

In the retranslation and harmonization stages, there were no changes in the questionnaire. The comprehension test was applied to 14 subjects, all mothers, with an average age of 30 years. In relation to the education level, 43% (n=6) had incomplete high school, 22% (n=3) incomplete elementary school, 14% (n=2) technical education, 14% (n=2) high school and 7% (n=1) undergraduate. Six of them were housewives, one was self-employed and worked at home and seven of them were employed. Of the 14 mothers, 11 completed the EMPATHIC-30 questionnaire with a dispersion of answer options of the Likert scale (1-6) demonstrating a spread in the answer options and can be presumed that parents understand the translated version. Two mothers scored only the maximum score of every item and one mother only used the option 1 or 6 of the Likert scale, which can be considered as a lack of understanding of the use of the questionnaire.

In the question “The IC-unit could easily be reached by telephone”, two mothers answered that they did not understand, one that never needed and three did not answer. Six assigned grade 6, one grade 1, and grade 4. The PICU of our hospital does not transmit information by telephone, so it was understood that the mothers did not understand the question. In this way the sentence was changed to "We could easily get information from the PICU over the phone when needed." The option “0 - not applicable” was also added to the Likert Scale, considering that most parents remained full time with patients during PICU stay.

Afterwards, the questionnaire was applied to five other parents for a second comprehension test, all mothers, with an average age of 41.6 years. The level of education was: one mother with high school, two mothers with incomplete high school,

one mother with incomplete elementary school, and one mother with higher education. Two of them were housewives and three were employed.

In this second test, all mothers answered the scale demonstrated to understand this version; three of them used the “0 - not applicable” in at least one of the items. The final version of the Brazilian translation of the EMPATHIC-30 questionnaire is shown in **Supplementary material 3**. The English version used in the table corresponds to the original text published by Latour et al. (7).

Validation

In the content-related validation stage by the expert committee, 29 questionnaires were delivered, of which 17 were returned. We included clinical multi-professional staff of the PICU.

Of the 17 questionnaires collected, one was excluded because the staff member was not part of the PICU team, and one for not having completed the questionnaire correctly, leaving the evaluation of 15 experts, as shown in **Supplementary material 4.**

Of these 15 experts, 33% (n=5) had postgraduate degrees, 7% (n=1) PhD and 13% (n=2) Masters, 27% (n=4) were physicians attending residency in pediatric intensive care, and the remaining 20% (n=3) had a degree. The average length of experience in PICU was 8.63 years.

From the experts' answers, the mean, SD and CVC of each item were calculated, as well as the total CVC of the instrument, as shown in **Supplementary material 5.**

The CVC above the cutoff point (> 0.8) was obtained in most items. Only 10% (n=3) of the items were below 0.8 (“There was enough room around our son's bed”, “We could easily get PICU information over the phone when needed” and “We could always stay close to our child, even during the procedures”). The mean of these items

was also low (3.3; 2.3; 3.3, respectively) and the SD high (1.5; 1.5; 1.6, respectively). However, considering the socioeconomic and cultural diversity of our country, the questions were kept in the questionnaire.

It is not routine in our hospital to provide information by telephone to family members, however, it is considered that in other PICUs of the country, this is necessary and used. We believe that the question “We could always stay close to our child, even during the procedures”, obtained a low CVC due to the fact that in our PICU, parents are asked to wait outside the PICU during medical rounds and procedures. However, considering the importance of evaluating parental satisfaction visioning improvements in the quality of care and patient- and family-centered care (PFCC), we kept this item.

The total CVC of the scale was 0.91, above the cutoff point, thus documenting the general validity of the questionnaire content.

Reliability

To assess reliability (internal consistency), we analyzed the responses of 141 parents/family members. The characteristics of patients and family members, as well as the results for internal consistency, are shown in Tables 1 and 2, respectively.

Table 1: Characteristics of the children and their families

Characteristics	n (%)
Characteristics of the relatives	
Person who completed the questionnaire (n=141)	
Mother	101 (71.6)
Father	29 (20.6)
Other	11 (7.8)
Age in years (medican and IQR) (n=141)	34 (26 - 41)
Education (n=141)	
Incomplete elementary school	34 (24.1)
Complete elementary school	13 (9.2)
Incomplete high school	14 (9.9)
Complete high school	44 (31.2)
Technical course	4 (2.8)
University graduate	26 (18.4)
Other	6 (4.3)
Residents in the house (medican and IQR) (n=141)	4 (3 - 5)
Civil status (n=139)	
Married	84 (60.4)
Not married	43 (30.9)
Divorced	5 (3.6)
Widower	7 (5.1)
Psychological assistance (n=139)	58 (41.7)
Time spent with the patient (n=135)	
24 hours	95 (70.4)
6 hours	38 (28.1)
3 hours	2 (1.5)
Public healthcare assistance (n=141)	93 (65.6)
Patients characteristics (n=141)	
Age in months (median and IQR)	35 (5 - 87)
Need for mechanical ventilation	28 (19.9)

Chronic disease	49 (34.8)
PICU length of stay in days (median and IQR)	3 (1 - 5)
First hospitalization	104 (73.8)

PICU: pediatric intensive care unit; IQR: median and interquartile range

Table 2 - Description of the scores, per domain

Domain	Mean score	Total score Mean (SD)	Cronbach's alpha	McDonald's ômega
Information	5.6 (0.5)	28.2 (2.7)	0.64 (0.55; 0.73)	0.68 (0.49; 0.88)
Care and treatment	5.7 (0.5)	45.7 (3.7)	0.77 (0.71; 0.83)	0.73 (0.61; 0.85)
Organization	5.6 (0.5)	28.1 (2.7)	0.47 (0.35; 0.59)	0.63 (0.47; 0.80)
Parenteral participation	5.7 (0.6)	34.0 (3.3)	0.72 (0.66; 0.78)	0.85 (0.76; 0.93)
Professional attitude	5.8 (0.4)	35.0 (2.2)	0.72 (0.65; 0.79)	0.72 (0.58; 0.86)
Total	5.9 (0.3)	165.5 (10.5)	0.90 (0.88; 0.92)	0.91 (0.88; 0.95)

SD: standard deviation

Supplementary material 6 shows the distribution of responses in each item of the questionnaire expressed in absolute and relative frequency. There is a low rate of missing values or cases where the participant considered the item as not applicable, except for items 15 (We could easily obtain information from the PICU by telephone when necessary) and item 16 (There was enough space around our child's bed), whose rates were 41.8% and 59.6%, respectively.

Supplementary material 7 shows the scale description of each item, showing the mean, standard deviation and Cronbach's alpha in case of item removal. It is observed that none of the items had an average value lower than 5 indicating high degrees of satisfaction.

Table 2 shows the descriptive analysis of domains in the form of domain mean value and total (sum of all items in the respective domain), the Cronbach's alpha and McDonald's omega. The Cronbach's alpha had a weighted mean value between domains of 0.70. Among the domains, Cronbach's alpha was lower than 0.60 in the Organization domain only, being 0.47 (95%CI 0.35; 0.59), which was also the domain with a higher non-response rate. Exclusion of individual items did not affect Cronbach's alpha substantially (**Supplementary material 7**).

The values of the other domains were 0.64 (95%CI: 0.55; 0.73) for information, 0.77 (95%CI: 0.71, 0.83) for care and treatment, 0.72 (95%CI: 0.66; 0.78) for participation and 0.72 (95%CI: 0.65; 0.79) for professional attitudes. The total internal consistency, independent of the domain, was 0.90 (I.C. 95%: 0.88; 0.92). Due to the difference in the number of respondents in each domain, the internal consistency of the questionnaire was measured by the weighted average of Cronbach's alpha, according to the number of respondents in each domain, resulting in 0.70, considered as good (13).

Validity

Table 3 demonstrates the relationship between the questionnaire items responses on domain level and the characteristics of the children (mechanical ventilation, first hospitalization and chronic disease). It was observed that parents of children in the first hospitalization are more likely to be satisfied with the domains care & treatment, parent participation and professional attitude. Additionally, considering the total of all items in

the questionnaire, parents of children with chronic disease are more likely to be satisfied.

Table 3: Overall Nondifferential Validity and Relationship between the questionnaire items responses and mechanical ventilation, first hospitalization and chronic disease

Domain	Yes Mean (SD)	No Mean (SD)	P-value
Mechanical ventilation			
Information	5.66 (0.43)	5.64 (0.57)	0.762
Care & Treatment	5.76 (0.36)	5.69 (0.49)	0.862
Organization	5.46 (0.89)	5.66 (0.44)	0.762
Parent Participation	5.55 (0.61)	5.69 (0.55)	0.186
Professional Attitude	5.79 (0.42)	5.86 (0.35)	0.488
Total	5.76 (0.23)	5.73 (0.38)	0.631
First hospitalization			
Information	5.66 (0.54)	5.59 (0.56)	0.406
Care & Treatment	5.75 (0.43)	5.59 (0.54)	0.026
Organization	5.62 (0.58)	5.65 (0.41)	0.645
Parent Participation	5.71 (0.53)	5.52 (0.63)	0.027
Professional Attitude	5.89 (0.29)	5.73 (0.49)	0.022
Total	5.71 (0.39)	5.83 (0.16)	0.793
Chronic disease			
Information	5.67 (0.52)	5.62 (0.56)	0.790
Care & Treatment	5.68 (0.55)	5.72 (0.42)	0.880
Organization	5.72 (0.62)	5.57 (0.49)	0.195
Parent Participation	5.58 (0.67)	5.70 (0.51)	0.640
Professional Attitude	5.83 (0.42)	5.85 (0.33)	0.805
Total	5.85 (0.29)	5.66 (0.37)	0.023

SD: standard deviation

Supplementary material 8 demonstrates the relationship between the domains of the questionnaire and psychological assistance, full-time presence with the patient and public health system. Data showed that parents of children from the public health system are more likely to be satisfied with the information received about their children than parents of children from private system. All other domains showed no significant differences between the variable indicating that the non-differential validity was sufficient and therefore the questionnaire is valid among a heterogeneous group of children and parents.

DISCUSSION

In Brazil, studies related to the assessment of parent's satisfaction in PICU are mostly qualitative research and no studies published so far have evaluated this indicator using validated questionnaires. Our study carried out the translation and cross-cultural adaptation and assessed the validation and reliability of the EMPATHIC-30 instrument for PICUs in Brazil.

The process of translation and cultural adaptation was performed using a specific scientific methodology (8) and was also used in the translation of EMPATHIC instruments in other countries (3, 14–16). To assess parental satisfaction in PICU, an EMPATHIC questionnaire was also designed for Neonatal Intensive Care Units (NICUs), the EMPHATIC-N (10). In our study, the changes made to the questionnaire items in the translation and cultural adaptation process were related to the word sequence in the sentences and the use of the most common words in our culture, in order to adapt the Portuguese syntax. These adaptations were performed considering also the translation and adaptation of EMPATHIC-N performed in Brazil (9).

In relation to the content-related validation, as in the study by Gomez et al. (2017), the item "The IC-unit could easily be reached by telephone" was not considered relevant by the experts (9). In Spain, this item was the one that obtained the highest “not applicable” response rate of the entire instrument (35%) (3), similar as in our study. Gill et al. also found such pattern of responses in Australia. In their study, the use of new communication technologies and the fact that parents stayed with their children during the entire hospitalization may explain that finding (16). In our study, we believe that the latter is the most likely explanation. Because of the cultural and socioeconomic diversity that exists within our country, that item and the item “There was enough space around our child's bed” were kept in the questionnaire. Since many PICUs in Brazil are organized as a single room with little space between beds and others still provide information by telephone, we believe that keeping the two questions in the questionnaire is appropriate.

The question that addresses parental presence during all PICU procedures in our study also obtained a similar results to the study conducted with the EMPATHIC-N questionnaire (9), which obtained a result below the cutoff point to consider content validity. Parents' presence with their child during hospitalization as well as during medical procedures should be encouraged by the professionals (9, 17). Family participation in rounds is one of the practices of the PFCC model. In the study by Bhansali et al (2013), parents were present in 72% of the rounds observed, but they were not involved in the discussions most of the time (18). Despite the implementation of the PFCC model has been growing worldwide, there is a large discrepancy between the PFCC model and practice and often parents are treated as visitors (19). The practice of parents stay in our PICU is not performed in its entirety, as they are asked to leave the unit during some procedures. Family members remain in the unit during the rounds

but are not invited to actively participate in it. In order to improve patient care and PFCC practice, we believe it is necessary to obtain the opinions of parents regarding this practice. As in our hospital, other institutions should also consider these PFCC practices. For this reason, we have decided to keep this item in the questionnaire.

Our study used the coefficients to assess internal consistency, Cronbrach's alpha and McDonald's omega. Cronbrach's alpha has been widely used to measure reliability of health-related outcome measure instruments. In our context, the McDonald's omega has been used as an additional alternative to measure the internal consistency (20). Our decision to use both coefficients was because alpha has been demonstrated to be representative of a measure's internal consistency only when the assumptions of the essentially tau-equivalent model are met (21). However, in practice, such requirements are seldom met (22, 23). Hence, the literature has been describing the omega as a more sensible index of internal consistency, in relation to alpha and also to other alternatives (21, 24, 25). Studies showed that in cases of tau-equivalent models, omega at least performs as well as the alpha, and under violations of tau-equivalence, omega outperforms alpha and is the preferred choice (11).

Within the context of healthcare, patient or parental satisfaction can be described as the degree to which they feel they have been provided with high-quality healthcare. If parents feel that their child has been provided with high-quality care, they are more likely to be satisfied, and vice versa. Thus, satisfaction measurement is an essential part of the evaluation of the quality of health services (26). The EMPATHIC-30 empowers parents to provide feedback on their experiences in PICU and may facilitate healthcare professionals to improve quality-of-care. Parental satisfaction outcome measures may serve as a valuable quality performance indicator and should therefore be widely implemented. We showed a high mean of satisfaction in some subdomains, unlike the

study by Latour et al. (2013) (7). The ceiling effect may be explained by the small size of our sample (141 vs. 3454) and the fact that 1/3 of our patients continued to be treated by the PICU medical staff in the ward. A similar result was demonstrated by Mol et al. in South Africa (27).

Brazil is a middle-income country of continental size where the profile and provision of care in PICUs has been poorly studied (28). In our study, most patients used the Brazilian public health system and were accompanied by their mothers, who stayed full time with their child. PICU admission is a traumatic event that changes family routine, and usually the mother is the one who takes the lead in this new setting (29). Within this context, which is likely to be applicable to most Brazilian PICUs, understanding parental satisfaction with a tool that was translated into a local language, culturally adapted and validated is fundamental to the process of empowering families. The EMPATHIC-30 questionnaire is able to evaluate the provision of clear information about the disease and the perception of quality, professional attitude and organization of care, as well as the direct participation of parents in the discussions about the care of their child. We believe that the use of such structured tools will improve the existing bonds between parents and healthcare teams, providing parents with greater critical reflection and autonomy over the care of their child, thus contributing to the overall improvement of care (30).

The translation, adaptation and validation process were performed in only one PICU of a teaching hospital in southern Brazil, so the cultural and socioeconomic diversity of the country can influence the cross-cultural adaptation. This study presents a number of validation and reliability tests of the Brazilian EMAPTHIC-30. However, not all steps of a full validation has been performed such as confirmatory factor analysis. A complete evaluation of the psychometric properties of the EMPATHIC-30

might be needed with a larger group of parents to confirm its validity to be used as a national quality outcome measure. In addition, although parents were involved in the translation and cultural adaptation process of the questionnaire, content analysis was performed with PICU staff which could have been replaced by end-users. This is a limitation that needs to be considered.

In conclusion, the results of our study support the use of the Brazilian version of EMPATHIC-30 for the evaluation of parents' satisfaction of children admitted to the PICU. We believe that the use of EMPATHIC-30 in Brazil can contribute to the evaluation of the quality-of-care provided in the PICU and future benchmarking is recommended among all PICUs in Brazil. Based on the results, it is expected that processes and behaviors that interfere with parental satisfaction can be reassessed, aiming at the improvement of care centered on the patient and the family, as well as reinforcing correct and humanized behaviors. Finally, the Brazilian version of EMPATHIC-30 seems a sensible parent reported outcome measure and can be considered in future research as a study outcome measure.

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Supplementary material 1: Brazilian version of the EMPATHIC-30 questionnaire

Item	Question
	Domínio informação
1	Todos os dias conversávamos com os médicos sobre o cuidado e o tratamento do nosso filho
2	Todos os dias conversávamos com os enfermeiros sobre o cuidado e o tratamento do nosso filho
3	O médico nos informou claramente sobre as consequências do tratamento do nosso filho
4	Recebemos informações claras sobre a realização e resultado dos exames e testes
5	Recebemos informações compreensíveis sobre os efeitos dos medicamentos
	Domínio Cuidado e Tratamento
6	Os médicos e enfermeiros trabalharam em conjunto
7	A equipe médica nos preparou bem para a alta do nosso filho
8	As enfermeiras nos prepararam bem para a alta do nosso filho
9	A equipe estava atenta à prevenção e ao tratamento da dor do nosso filho
10	Os médicos levaram em conta o conforto do nosso filho
11	Os enfermeiros levaram em conta o conforto do nosso filho
12	Todos os dias sabíamos quem era o médico responsável pelo nosso filho

13 Todos os dias sabíamos quem era a enfermeira responsável pelo nosso filho

Domínio organização

14 A equipe trabalhou de forma eficiente

15 Podíamos facilmente obter informações da UTIP por telefone quando necessário

16 Havia espaço suficiente ao redor da cama do nosso filho

17 A UTI estava limpa

18 O barulho da UTI era abafado na medida do possível

Domínio participação dos pais

19 Durante a nossa permanência a equipe perguntou regularmente sobre como estávamos nos sentindo

20 A equipe nos envolveu ativamente na tomada de decisões sobre cuidado e tratamento do nosso filho

21 Fomos incentivados a permanecer perto do nosso filho

22 Tínhamos confiança nos médicos

23 Tínhamos confiança nos enfermeiros

24 Sempre pudemos permanecer perto do nosso filho, mesmo durante os procedimentos

Domínio atitude dos profissionais

25 Recebemos apoio dos médicos

26	Recebemos apoio dos enfermeiros
27	A equipe trabalhou com higiene
28	A equipe respeitou a privacidade do nosso filho e a nossa
29	A equipe demonstrou respeito por nosso filho e por nós
30	Fomos bem acolhidos na chegada à UTI

Supplementary material 2: Modified words in the reconciliation phase (available only in Portuguese).

Translation	Reconciliation
1. Tivemos conversas diárias sobre o cuidado e o tratamento do nosso filho com os médicos	*1. Todos os dias conversávamos com os médicos sobre o cuidado e o tratamento do nosso filho*
2. Tivemos conversas diárias sobre o cuidado e o tratamento do nosso filho com os enfermeiros	*2. Todos os dias conversávamos com os enfermeiros sobre o cuidado e o tratamento do nosso filho*
4. Recebemos informações claras sobre exames e testes	*4. Recebemos informações claras sobre a realização e resultado dos exames e testes*
6. Os médicos e enfermeiros trabalharam em estreita colaboração	*6. Os médicos e enfermeiros trabalharam em conjunto*
7. Estávamos bem preparados para a alta do nosso filho pelos médicos	*7. A equipe médica nos preparou bem para a alta do nosso filho*
8. Estávamos bem preparados para a alta do nosso filho pelos enfermeiros	*8. As enfermeiras nos prepararam bem para a alta do nosso filho*

10. O conforto do nosso filho foi levado em conta pelos médicos	*10. Os médicos levaram em conta o conforto do nosso filho*
11. O conforto do nosso filho foi levado em conta pelos enfermeiro	*11. Os enfermeiros levaram em conta o conforto do nosso filho*
12. Todos os dias sabíamos quem era o responsável pelo nosso filho, com relação aos médicos	*12. Todos os dias sabíamos quem era o médico responsável pelo nosso filho*
13. Todos os dias sabíamos quem era o responsável pelo nosso filho, com relação aos enfermeiros	*13. Todos os dias sabíamos quem era a enfermeira responsável pelo nosso filho*
19. Durante a nossa permanência, os funcionários perguntaram regularmente sobre a nossa experiência	*19. Durante a nossa permanência a equipe perguntou regularmente sobre como estávamos nos sentindo*
20. Fomos ativamente envolvidos na tomada de decisões sobre cuidado e tratamento do nosso filho	*20. A equipe nos envolveu ativamente na tomada de decisões sobre cuidado e tratamento do nosso filho*
24. Mesmo durante procedimentos intensivos, sempre pudemos permanecer perto do nosso	*24. Sempre pudemos permanecer perto do nosso filho, mesmo durante*

filho	*os procedimentos*
30. Na admissão, fomos bem recebidos	*30. Fomos bem acolhidos na chegada à UTI*

Supplementary material 3 – Empathic 30 in the original English version in English and in the final Brazilian version

Item	English version	Brazilian version
1	We had daily talks about our child's care and treatment with the doctors	**Todos os dias conversávamos com os médicos sobre o cuidado e o tratamento do nosso filho**
2	We had daily talks about our child's care and treatment with the nurses	**Todos os dias conversávamos com os enfermeiros sobre o cuidado e o tratamento do nosso filho**
3	The doctor clearly informed us about the consequences of our child's treatment	**O médico nos informou claramente sobre as consequências do tratamento do nosso filho**
4	We received clear information about the examinations and tests	**Recebemos informações claras sobre a realização e resultado dos exames e testes**
5	We received understandable information about the effects of the drugs	**Recebemos informações compreensíveis sobre os efeitos dos medicamentos**
6	The doctors and nurses worked closely together	**Os médicos e enfermeiros trabalharam em conjunto**
7	We were well prepared for our child's discharge by the doctors	**A equipe médica nos preparou bem para a alta do nosso filho**

8	We were well prepared for our child's discharge by the nurses	**As enfermeiras nos prepararam bem para a alta do nosso filho**
9	The team was alert to the prevention and treatment of pain in our child	**A equipe estava atenta à prevenção e ao tratamento da dor do nosso filho**
10	Our child's comfort was taken into account by the doctors	**Os médicos levaram em conta o conforto do nosso filho**
11	Our child's comfort was taken into account by the nurses	**Os enfermeiros levaram em conta o conforto do nosso filho**
12	Every day we knew who was responsible for our child, regarding the doctors	**Todos os dias sabíamos quem era o médico responsável pelo nosso filho**
13	Every day we knew who was responsible for our child, regarding the nurses	**Todos os dias sabíamos quem era a enfermeira responsável pelo nosso filho**
14	The team worked efficiently	**A equipe trabalhou de forma eficiente**
15	The IC-unit could easily be reached by telephone	**Podíamos facilmente obter informações da UTIP por telefone quando necessário**
16	There was enough space around our child's bed	**Havia espaço suficiente ao redor da cama do nosso filho**
17	The IC-unit was clean	**A UTI estava limpa**
18	Noise in the UC-unit was muffled as good as possible	**O barulho da UTI era abafado na medida do possível**

19	During our stay the staff regularly asked for our experiences	**Durante a nossa permanência a equipe perguntou regularmente sobre como estávamos nos sentindo**
20	We were actively involved in decision-making on care and treatment of our child	**A equipe nos envolveu ativamente na tomada de decisões sobre cuidado e tratamento do nosso filho**
21	We were encouraged to stay close to our child	**Fomos incentivados a permanecer perto do nosso filho**
22	We had confidence in the doctors	**Tínhamos confiança nos médicos**
23	We had confidence in the nurses	**Tínhamos confiança nos enfermeiros**
24	Even during intensive procedures we could always stay close to our child	**Sempre pudemos permanecer perto do nosso filho, mesmo durante os procedimentos**
25	We received sympathy from the doctors	**Recebemos apoio dos médicos**
26	We received sympathy from the nurses	**Recebemos apoio dos enfermeiros**
27	The team worked hygienically	**A equipe trabalhou com higiene**
28	The team respected the privacy of our child and of us	**A equipe respeitou a privacidade do nosso filho e a nossa**
29	The team showed respect for our child and for us	**A equipe demonstrou respeito por nosso filho e por nós**

30	At admission we felt welcome	**Fomos bem acolhidos na chegada à UTI**

Supplementary material 4: Experts qualifications.

Experts	N
Physician	2
Nurse	3
Psychologist	1
Physiotherapist	2
Researcher nutritionist	2
Resident physician	4
Resident physiotherapist	1
Total	15

Supplementary material 5: Mean, standard deviation and content validity coefficient per item.

Item	Mean	SD	CVC
Informação (*English version:* Information)			
Todos os dias conversávamos com os médicos sobre o cuidado e o tratamento do nosso filho (*English version:* We had daily talks about our child's care and treatment with the doctors)	4.9	0.3	0.99
Todos os dias conversávamos com os enfermeiros sobre o cuidado e o tratamento do nosso filho (*English version:* We had daily talks about our child's care and treatment with the nurses)	4.5	1.1	0.89
O médico nos informou claramente sobre as consequências do tratamento do nosso filho (*English version:* The doctor clearly informed us about the consequences of our child's treatment)	5.0	0.0	1.00
Recebemos informações claras sobre a realização e resultado dos exames e testes (*English version:* We received clear	4.9	0.3	0.99

information about the examinations and tests)			
Recebemos informações compreensíveis sobre os efeitos dos medicamentos (*English version:* We received understandable information about the effects of the drugs)	4.9	0.4	0.97
Cuidado e tratamento (*English version:* Care & treatment)			
Os médicos e enfermeiros trabalharam em conjunto (*English version:* The doctors and nurses worked closely together)	4.7	0.6	0.93
A equipe médica nos preparou bem para a alta do nosso filho (*English version:* We were well prepared for our child's discharge by the doctors)	4.8	0.6	0.96
As enfermeiras nos prepararam bem para a alta do nosso filho (*English version:* We were well prepared for our child's discharge by the nurses)	4.7	1.0	0.93

A equipe estava atenta à prevenção e ao tratamento da dor do nosso filho (*English version:* The team was alert to the prevention and treatment of pain in our child)	4.6	0.8	0.92
Os médicos levaram em conta o conforto do nosso filho (*English version:* Our child's comfort was taken into account by the doctors)	5.0	0.0	1.00
Os enfermeiros levaram em conta o conforto do nosso filho (*English version:* Our child's comfort was taken into account by the nurses)	5.0	0.0	1.00
Todos os dias sabíamos quem era o médico responsável pelo nosso filho (*English version:* Every day we knew who was responsible for our child, regarding the doctors)	4.5	1.1	0.89
Todos os dias sabíamos quem era a enfermeira responsável pelo nosso filho (*English version:* Every day we knew who was responsible for our child, regarding the nurses)	4.5	1.1	0.89

Organização (*English version:* Organization)			
A equipe trabalhou de forma eficiente (*English version:* The team worked efficiently)	4.9	0.4	0.97
Podíamos facilmente obter informações da UTIP por telefone quando necessário (*English version:* The IC-unit could easily be reached by telephone)	2.3	1.5	0.45
Havia espaço suficiente ao redor da cama do nosso filho (*English version:* There was enough space around our child's bed)	3.3	1.5	0.67
A UTI estava limpa (*English version:* The IC-unit was clean)	4.3	1.1	0.87
O barulho da UTI era abafado na medida do possível (*English version:* Noise in the UC-unit was muffled as good as possible)	4.3	1.2	0.85
Participação dos pais (*English version:* Parent participation)			

Durante a nossa permanência a equipe perguntou regularmente sobre como estávamos nos sentindo (*English version:* During our stay the staff regularly asked for our experiences)	4.6	0.5	0.92
A equipe nos envolveu ativamente na tomada de decisões sobre cuidado e tratamento do nosso filho (*English version:* We were actively involved in decision-making on care and treatment of our child)	4.5	1.1	0.91
Fomos incentivados a permanecer perto do nosso filho (*English version:* We were encouraged to stay close to our child)	4.7	0.5	0.95
Tínhamos confiança nos médicos (*English version:* We had confidence in the doctors)	5.0	0.0	1.00
Tínhamos confiança nos enfermeiros (*English version:* We had confidence in the nurses)	5.0	0.0	1.00
Sempre pudemos permanecer perto do nosso filho, mesmo durante os procedimentos (*English version:* Even	3.3	1.6	0.65

during intensive procedures we could always stay close to our child)			
Atitude dos profissionais (*English version:* Professional attitude)			
Recebemos apoio dos médicos (*English version:* We received sympathy from the doctors)	4.9	0.4	0.97
Recebemos apoio dos enfermeiros (*English version:* We received sympathy from the nurses)	4.9	0.4	0.97
A equipe trabalhou com higiene (*English version:* The team worked hygienically)	4.5	1.1	0.89
A equipe respeitou a privacidade do nosso filho e a nossa (*English version:* The team respected the privacy of our child and of us)	4.3	1.1	0.87
A equipe demonstrou respeito por nosso filho e por nós (*English version:* The team showed respect for our child and for us)	5.0	0.0	1.00

Fomos bem acolhidos na chegada à UTI (*English version:* At admission, we felt welcome)	4.9	0.3	0.99

Note: The English version in this table corresponds to the original sentences published by Latour et al, 2011 (12).

Supplementary material 6: Frequency of responses for each item of the questionnaire

Item	Question	Number of assessments N(%)
1	**Todos os dias conversávamos com os médicos sobre o cuidado e o tratamento do nosso filho** (*English version:* We had daily talks about our child's care and treatment with the doctors)	140 (99.3)
2	**Todos os dias conversávamos com os enfermeiros sobre o cuidado e o tratamento do nosso filho** (*English version:* We had daily talks about our child's care and treatment with the nurses)	141 (100)
3	**O médico nos informou claramente sobre as consequências do tratamento do nosso filho** (*English version:* The doctor clearly informed us about the consequences of our child's treatment)	141 (100)
4	**Recebemos informações claras sobre a realização e resultado dos exames e testes** (*English version:* We received clear information about the examinations and tests)	135 (95.7)
5	**Recebemos informações compreensíveis sobre os efeitos dos medicamentos** (*English version:* We received understandable information about the effects of the drugs)	135 (95.7)

6	**Os médicos e enfermeiros trabalharam em conjunto** (*English version:* The doctors and nurses worked closely together)	140 (99.3)
7	**A equipe médica nos preparou bem para a alta do nosso filho** (*English version:* We were well prepared for our child's discharge by the doctors)	139 (98.6)
8	**As enfermeiras nos prepararam bem para a alta do nosso filho** (*English version:* We were well prepared for our child's discharge by the nurses)	137 (97.2)
9	**A equipe estava atenta à prevenção e ao tratamento da dor do nosso filho** (*English version:* The team was alert to the prevention and treatment of pain in our child)	140 (99.3)
10	**Os médicos levaram em conta o conforto do nosso filho** (*English version:* Our child's comfort was taken into account by the doctors)	141 (100)
11	**Os enfermeiros levaram em conta o conforto do nosso filho** (*English version:* Our child's comfort was taken into account by the nurses)	141 (100)
12	**Todos os dias sabíamos quem era o médico responsável pelo nosso filho** (*English version:* Every day we knew who was responsible for our child, regarding the doctors)	133 (94.3)

13	**Todos os dias sabíamos quem era a enfermeira responsável pelo nosso filho** (*English version:* Every day we knew who was responsible for our child, regarding the nurses)	138 (97.9)
14	**A equipe trabalhou de forma eficiente** (*English version:* The team worked efficiently)	141 (100)
15	**Podíamos facilmente obter informações da UTIP por telefone quando necessário** (*English version:* The IC-unit could easily be reached by telephone)	82 (58.2)
16	**Havia espaço suficiente ao redor da cama do nosso filho** (*English version:* There was enough space around our child's bed)	57 (40.4)
17	**A UTI estava limpa** (*English version:* The IC-unit was clean)	141 (100)
18	**O barulho da UTI era abafado na medida do possível** (*English version:* Noise in the UC-unit was muffled as good as possible)	137 (97.2)
19	**Durante a nossa permanência a equipe perguntou regularmente sobre como estávamos nos sentindo** (*English version:* During our stay the staff regularly asked for our experiences)	126 (89.4)
20	**A equipe nos envolveu ativamente na tomada de decisões sobre cuidado e tratamento do nosso filho** (*English version:*	136 (96.4)

	We were actively involved in decision-making on care and treatment of our child)	
21	**Fomos incentivados a permanecer perto do nosso filho** (*English version:* We were encouraged to stay close to our child)	134 (95.0)
22	**Tínhamos confiança nos médicos** (*English version:* We had confidence in the doctors)	141 (100)
23	**Tínhamos confiança nos enfermeiros** (*English version:* We had confidence in the nurses)	141 (100)
24	**Sempre pudemos permanecer perto do nosso filho, mesmo durante os procedimentos** (*English version:* Even during intensive procedures we could always stay close to our child)	138 (97.9)
25	**Recebemos apoio dos médicos** (*English version:* We received sympathy from the doctors)	141 (100)
26	**Recebemos apoio dos enfermeiros** (*English version:* We received sympathy from the nurses)	141 (100)
27	**A equipe trabalhou com higiene** (*English version:* The team worked hygienically)	141 (100)
28	**A equipe respeitou a privacidade do nosso filho e a nossa** (*English version:* The team respected the privacy of our child and of us)	140 (99.3)

29	**A equipe demonstrou respeito por nosso filho e por nós** (*English version:* The team showed respect for our child and for us)	140 (99.3)
30	**Fomos bem acolhidos na chegada à UTI** (*English version:* At admission we felt welcome)	141 (100)

Supplementary material 7: Descriptive analysis per item

Item	n	Mean	SD	Cronbach's alpha if items were removed
Informação (*English version:* Information)				
Todos os dias conversávamos com os médicos sobre o cuidado e o tratamento do nosso filho (*English version:* We had daily talks about our child's care and treatment with the doctors)	140	5.8	0.6	0.90
Todos os dias conversávamos com os enfermeiros sobre o cuidado e o tratamento do nosso filho (*English version:* We had daily talks about our child's care and treatment with the nurses)	141	5.7	0.7	0.90
O médico nos informou claramente sobre as consequências do tratamento do nosso filho (*English version:* The doctor clearly informed us about the consequences of our child's treatment)	141	5.7	0.8	0.90

Recebemos informações claras sobre a realização e resultado dos exames e testes (*English version:* We received clear information about the examinations and tests)	135	5.4	1.1	0.90
Recebemos informações compreensíveis sobre os efeitos dos medicamentos (*English version:* We received understandable information about the effects of the drugs)	135	5.5	1.0	0.90
Cuidado e tratamento (*English version:* Care & treatment)				
Os médicos e enfermeiros trabalharam em conjunto (*English version:* The doctors and nurses worked closely together)	140	5.8	0.6	0.90
A equipe médica nos preparou bem para a alta do nosso filho (*English version:* We were well prepared for our child's discharge by the doctors)	139	5.6	0.8	0.90
As enfermeiras nos prepararam bem para a alta do nosso filho (*English*	137	5.6	0.8	0.90

version: We were well prepared for our child's discharge by the nurses)				
A equipe estava atenta à prevenção e ao tratamento da dor do nosso filho (*English version:* The team was alert to the prevention and treatment of pain in our child)	140	5.8	0.6	0.90
Os médicos levaram em conta o conforto do nosso filho (*English version:* Our child's comfort was taken into account by the doctors)	141	5.8	0.6	0.90
Os enfermeiros levaram em conta o conforto do nosso filho (*English version:* Our child's comfort was taken into account by the nurses)	141	5.7	0.7	0.90
Todos os dias sabíamos quem era o médico responsável pelo nosso filho (*English version:* Every day we knew who was responsible for our child, regarding the doctors)	133	5.6	1.0	0.90
Todos os dias sabíamos quem era a enfermeira responsável pelo nosso filho	138	5.7	0.8	0.90

(*English version:* Every day we knew who was responsible for our child, regarding the nurses)				
Organização (*English version:* Organization)				
A equipe trabalhou de forma eficiente (*English version:* The team worked efficiently)	141	5.8	0.5	0.90
Podíamos facilmente obter informações da UTIP por telefone quando necessário (*English version:* The IC-unit could easily be reached by telephone)	82	5.0	1.6	0.90
Havia espaço suficiente ao redor da cama do nosso filho (*English version:* There was enough space around our child's bed)	57	5.7	0.8	0.90
A UTI estava limpa (*English version:* The IC-unit was clean)	141	5.9	0.5	0.90
O barulho da UTI era abafado na medida do possível (*English version:* Noise in the UC-unit was muffled as good as possible)	137	5.5	1.1	0.90

Participação dos pais (*English version:* Parent participation)				
Durante a nossa permanência a equipe perguntou regularmente sobre como estávamos nos sentindo (*English version:* During our stay the staff regularly asked for our experiences)	126	5.2	1.4	0.89
A equipe nos envolveu ativamente na tomada de decisões sobre cuidado e tratamento do nosso filho (*English version:* We were actively involved in decision-making on care and treatment of our child)	136	5.5	1.0	0.89
Fomos incentivados a permanecer perto do nosso filho (*English version:* We were encouraged to stay close to our child)	134	5.7	0.8	0.90
Tínhamos confiança nos médicos (*English version:* We had confidence in the doctors)	141	5.9	0.5	0.90
Tínhamos confiança nos enfermeiros (*English version:* We had confidence in the nurses)	141	5.9	0.5	0.90

Sempre pudemos permanecer perto do nosso filho, mesmo durante os procedimentos (*English version:* Even during intensive procedures we could always stay close to our child)	138	5.6	1.0	0.90
Atitude dos profissionais (*English version:* Professional attitude)				
Recebemos apoio dos médicos (*English version:* We received sympathy from the doctors)	141	5.8	0.6	0.90
Recebemos apoio dos enfermeiros (*English version:* We received sympathy from the nurses)	141	5.8	0.6	0.90
A equipe trabalhou com higiene (*English version:* The team worked hygienically)	141	5.9	0.5	0.90
A equipe respeitou a privacidade do nosso filho e a nossa (*English version:* The team respected the privacy of our child and of us)	140	5.8	0.6	0.90
A equipe demonstrou respeito por nosso filho e por nós (*English version:*	140	5.8	0.5	0.90

The team showed respect for our child and for us)				
Fomos bem acolhidos na chegada à UTI (*English version:* At admission, we felt welcome)	141	5.9	0.6	0.90

Note: The English version in this table corresponds to the original sentences published by Latour et al, 2011(12).

Supplementary material 8: Overall Nondifferential Validity and Relationship between the questionnaire and psychological assistance, full-time with the patient and public assistance

Domain	Yes Mean (SD)	No Mean (SD)	P-value
Psychological assistance			
Information	5.75 (0.39)	5.57 (0.62)	0.121
Care & Treatment	5.74 (0.39)	5.69 (0.52)	0.988
Organization	5.65 (0.64)	5.63 (0.45)	0.453
Parent Participation	5.72 (0.49)	5.61 (0.62)	0.183
Professional Attitude	5.8 (0.38)	5.87 (0.35)	0.487
Total	5.82 (0.26)	5.7 (0.4)	0.271
Full-time presence with the patient			
Information	5.64 (0.58)	5.68 (0.44)	0.940
Care & Treatment	5.7 (0.49)	5.77 (0.32)	0.917
Organization	5.72 (0.43)	5.34 (0.85)	0.121
Parent Participation	5.65 (0.6)	5.71 (0.48)	0.583
Professional Attitude	5.86 (0.36)	5.81 (0.39)	0.258

Total	5.78 (0.34)	5.82 (0.18)	0.678
Public health system			
Information	5.71 (0.45)	5.51 (0.67)	0.036
Care & Treatment	5.77 (0.39)	5.6 (0.57)	0.090
Organization	5.67 (0.4)	5.56 (0.74)	0.604
Parent Participation	5.73 (0.49)	5.52 (0.67)	0.097
Professional Attitude	5.86 (0.33)	5.8 (0.41)	0.321
Total	5.74 (0.31)	5.72 (0.42)	0.918

SD: standard deviation