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Quantum Caring for Parents: Translation and Adaptation of a Mobile Application into Portuguese

Quantum Caring for Parents: Tradução e adaptação da aplicação móvel para português Quantum Caring for Parents: Traducción y adaptación de la aplicación móvil al portugués

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ABSTRACT:

Objective: To translate and adapt the *Quantum Care for Parents - Neonatal Intensive Care Unit* mobile application to the Portuguese language and culture.

Method: Methodological study that covered the stages of translation, synthesis of translations, back translation, synthesis of back translations, evaluation by 20 neonatology experts to validate content, and pilot test, applied to 20 Portuguese parents with children hospitalized in the neonatology unit. The content validity was carried using the Lawshe Model and, for the lexicographic analysis of the content of the experts' suggestions, the IRaMuTeQ software was used.

Results: The evaluation criteria were semantic, cultural and conceptual equivalence between the original app and the translation. Content validity was good for the number of experts. The following classes emerged from the lexicographical analysis of the suggestions: Adequacy of the information, Availability of information for the parents, Simplification of information for the parents, and Facilitating the use of the app. In the pilot test, all items were classified as clear.

Conclusion: The mobile application showed validity of content indicative of a good adaptation into the Portuguese language and culture, and, after the introduction of the experts' suggestions and the pilot test, it is considered a good resource to support health education and parental health literacy in the neonatology unit.

Keywords: Neonatology; Nursing; Parents; Health Education; Validation Studies; Health Literacy.

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RESUMO:

Objetivo: Traduzir e adaptar para a língua e cultura portuguesa a aplicação móvel *Quantum Care for Parents- Neonatal Intensive Care Unit.*

Método: Estudo metodológico que contemplou as etapas de tradução, síntese das traduções, retroversão, síntese das retroversões, avaliação por 20 peritos em neonatologia para fazer a validação de conteúdo, e teste piloto aplicado a 20 pais portugueses com filhos internados na unidade de neonatologia. A validade de conteúdo foi suportada pelo Modelo de *Lawshe* e para a análise lexicográfica do conteúdo das sugestões dos peritos, recorreu-se ao *software* IRaMuTeQ.

Resultados: Os critérios de avaliação foram a equivalência semântica, cultural e concetual entre a app original e a tradução. A Validade de Conteúdo foi boa para o número de peritos. Da análise lexicográfica das sugestões emergiram as classes: Adequação da informação, Disponibilização da Informação aos pais, Simplificação da Informação e Facilitação da Usabilidade. No teste piloto todos os itens foram classificados como claros.

Conclusão: A aplicação móvel apresentou validade de conteúdo indicativa de boa adaptação à língua e cultura portuguesa e, após a introdução das sugestões dos peritos e teste piloto, considera-se um bom recurso de apoio à educação para a saúde e literacia parental em saúde, na unidade de neonatologia.

Palavras chave: Neonatologia; Enfermagem; Pais; Educação em Saúde; Estudos de Validação; Literacia em Saúde.

RESUMEN:

Objetivo: Traducir y adaptar para la lengua y cultura portuguesa la aplicación móvil Quantum Care for Parents - Neonatal Intensive Care Unit.

Metodología: Estudio metodológico que contemplo las etapas de traducción, síntesis de las traducciones, retroversión, síntesis de las retroversiones, evaluación por 20 peritos en neonatología para hacer la validación de contenidos y prueba piloto aplicada a 20 padres portugueses con hijos internados en la unidad de neonatología. La validez del contenido se apoyó en el Modelo de Lawshe y para el análisis lexicográfico del contenido de las sugerencias de los peritos se utilizó el software IRaMuTeQ.

Resultados: Los criterios de evaluación fueron la equivalencia semántica, cultural y conceptual entre la app original y la traducción. La validez del contenido fue buena para el número de peritos. Del análisis lexicográfico de las sugerencias emergen las clases: Adecuación de la información, Disponibilidad de la información para los padres, Simplificación de la información y Facilitación del uso. En la prueba piloto, todos los elementos se clasificaron como claros.

Conclusión: La aplicación móvil mostró validez de contenido indicativo de buena adaptación a la lengua y cultura portuguesa y, tras la introducción de las sugerencias de los peritos y de la prueba piloto, se considera un buen recurso de apoyo a la

educación para la salud y a la alfabetización parental en salud en la unidad de neonatología.

Palabras clave: Neonatología; Enfermería; Padres; Educación para la Salud; Estudios de Validación; Alfabetización en Salud.

INTRODUCTION

The admission of a newborn in the Neonate Unit (NU) is a traumatic event for both parents and family ⁽¹⁾. From the perspective of Meleis's Middle-Range Theory of Transition, the parents face multiple and unique challenges, due to which the transition into parenthood takes place later ⁽²⁾. Since the family is part of the care for the development of the newborn, it is important to bring into the NU the philosophy of Care Focused on the Family (CFF), which encourages the collaboration and involvement of the parents in the care for their children ^(3,4). However, the implementation of this philosophy has been inconsistent ⁽³⁾, despite the growing scientific evidence about the need to improve parent support, the involvement of parents in the decision making process, and the participation of the father in the care ⁽⁵⁾, respecting the principles of information sharing ⁽⁴⁾.

In practice, fathers value the information transmitted in the NU. They feel emotionally supported ⁽⁶⁾, involved in the care ⁽⁷⁾ and in the process of becoming a father ⁽⁸⁾. However,

the health professionals should be aware of the level of Health Literacy (HL) ⁽⁹⁾ of the parents, that is, of their capacity to understand and assimilate specialized health information, while also considering their emotional state ⁽¹⁰⁾. These factors will help them making informed decisions.

HL is the ability to acquire, understand, and use the information in health to make decisions about health in many contexts ⁽¹¹⁾. It is relevant to develop innovative educational practices that promote HL ⁽¹²⁾, especially concerning interactive and critical HL, since the traditional educational methods focus only on its more functional side ⁽¹¹⁾. In the NU, the parents have preferred interactive methodologies, especially the Internet and the mobile applications (apps)⁽¹³⁾, to the detriment of books or booklets, to acquire information in health⁽¹⁴⁾. They support the introduction of the apps in this context ⁽¹⁵⁾ due to their ability to provide information in an interactive, attractive, and easy to use way, adequate to each one's rhythm, style, and learning needs ⁽¹⁶⁾. The NU are also interested in implementing digital technologies, especially the apps, since they are a way to promote and expand the CFF ⁽¹⁷⁾, especially for people with low HL ⁽¹⁰⁾ levels, such as parents in the NU ^(9,18).

Understanding parenthood in the NU, as a transition of situational development ⁽²⁾, makes it possible to understand the inadequate HL level of the parents as something that can inhibit the process of transition and the adoption of educational practices for health, and digital technologies based on the CFF principles are seen here as facilitating conditions.

Considering the above, it is relevant to develop health education practices based on evidence that can contribute to promote the HL of parents in the NU with the help of digital technologies. The objective of this study was to translate and adapt, for the Portuguese culture and language, the app *Quantum Caring for Parents - Neonatal Intensive Care Unit (QCP-NICU)*.

MATERIALS AND METHOD

A systematic review of literature ⁽¹⁹⁾ found 18 applications for parents with children in the NU. These were evaluated in terms of quality, and the QCP-NICU received the highest score, followed by the apps *MyPreemie*, *NICU Companion*, *Babble*, and *Integrated Family Delivered Care*. In addition to the quality evaluation, it is important to highlight that this app receives support from the Model of the Universe of Age-Appropriate Care⁽²⁰⁾, which is one of the theoretical frameworks for NU care.

This app, seen in figure 1, was developed by *Caring Essentials Collaborative*, *LLC* ⁽²¹⁾, with the aim of developing, educating, and training parents by making information available according with their own pace. An investigative team started its validation and adaptation in London, but their results are yet to be published.

Figure 1. Quantum Caring for Parents - Neonatal Intensive Care Unit app



The app addresses seven dimensions: (1) My first home, with information on the environment and professionals; (2) Family, with information on the relationship with the newborn, the kangaroo care, postpartum depression, and acute stress; (3) Sleep, which addresses safe sleep and the stages of sleep; (4) Feeding and growing, which includes information on the oral abilities and feeding strategies; (5) Position and mobility, in bed and while holding the baby; (6) Skin of the baby, including the physiology of the skin, protection and hygiene strategies; and (7) Pain and stress, which describes the concepts of evaluation and the pharmacological and non-pharmacological measures. This is the content in the app that is adequate for the development of the abilities of the parents in the caring for their children and in a safe transition to home (20). Since it is only available in English, it is necessary to translate and culturally adapt it to Portuguese. Therefore, we have developed a methodological study, following the guidance of Sousa and Rojjanasrirat (2011) (22), to translate and adapt this health instrument between cultures, which happened from September 2019 to November 2020.

After the owner of the author rights for the app *QCP-NICU* gave her consent (although the copyright register is yet to be concluded), we started the study, which followed the steps: translation from English into Portuguese and comparison of the two translated versions (TL1 and TL2); synthesis I: back translation, and comparison of the two back translated versions (B-TL1 e B-TL2); synthesis II, evaluation by experts of the content of the app and qualitative analysis of the suggestions of change. Then, the pilot test was carried out, and the perception of the parents about the app, with regard to the clarity of its content, was evaluated.

Stage 1: Translation from English to Portuguese

In the first stage, the original English version of the app was translated into Portuguese (TL1 and TL2), with the participation of two bilinguals, bicultural translators, whose mother language is Portuguese. One of them was versed on the health field, while the other was more trained in the linguistic and cultural fields. Neither knew the original app nor the objectives of this study. Each translator received guidance to carry out their work, which should be focused on semantic equivalence. No information was exchanged

between the translators during the process of translation. They received explanations about the main objective of translation in the app by the main investigator. The background of the translators was different in regard to health knowledge. The first translator was a nurse, who was familiar with the terminology and the context of the NU. This allowed her to elaborate a translation that was adapted to the phenomenon being studied from a clinical perspective. The second translator was a teacher with 20 years' experience teaching English and Portuguese. Since she did not have the influence of the assumptions from previous knowledge in the neonate field, the translation she provided was pure and literal.

Stage 2: Synthesis of the Translations

Later, with the contribution of an independent and bilingual translator, both translated versions (TL1 and TL2) were compared with one another, and each was separately compared with the original version in the app. All ambiguities, discrepancies, sentences, and meanings detected were debated and corrected by the three translators and the main investigators, to reach the first preliminary translated version of the app QCP-NICU (PI-TL).

Stage 3: Back Translation

Two back translations were carried out (B-TL1 and B-TL2) by two other independent translators, whose qualification and experience were similar to those of stage 1, and whose mother language was English. The first translator was also a nurse, familiar with the specific NU terminology and context. The second was a teacher with about 10 years' experience in teaching English and Portuguese.

Stage 4: Synthesis of the Back Translations

Both back translations (B-TL1 and B-TL2) were compared with one another and with the original version by a multidisciplinary committee formed by one methodologist, one neonate nurse, all translators from the previous stages, and the author of the app, which led to the pre-final version of the adapted app. The objective of this stage was to guarantee semantic, cultural, and conceptual equivalence, leading to content validity. The content was reformulated with the suggestions, until there were no more ambiguities or discrepancies, and the pre-final version of the QCP-NICU (P-FTL) was produced.

Stage 5: Evaluation by experts and pilot test

The pre-final Portuguese version, produced in the previous stage, was submitted to the appreciation of 20 specialists for content validation. Since scientific literature does not provide any consensus with regard to what constitutes an expert ⁽²³⁾, we used the variables professional experience (above five years old in the neonate field) and the professional category (nurse and physicians). Furthermore, the mother language of the experts had to be Portuguese, and they had to be available to participate in the study.

In December 2019, the experts that were in accordance with inclusion criteria were invited, in person, to participate in the study. They received a written invitation that explained the objectives of the translation of the app, and what their collaboration would be. After the expert agreed to participate by signing the Free and Informed Consent Form, a moment was scheduled to carry out the evaluation in a calm environment of their choosing. Each expert received a mobile phone with the app, a document to

evaluate it with instructions on how to fill it in, and an evaluation grid. The latter allowed them to evaluate the app with regard to its clarity, from 1 to 3 (1 - it is not necessary for the clarity of the app; 2 - useful, but not necessary for the clarity of the app; 3 - essential for the clarity of the app). A space was also available for them to insert suggestions that could make the translation more precise, clearer, easier to understand, or more gramatically correct.

The content validity was quantitative, and carried out with the aid of the Lawshe Model ⁽²⁴⁾. The text *corpus* resulting from the transcription of the suggestions of the experts underwent a lexicographical textual analysis using the IRaMuTeQ (*Interface de R Pour Analyses Multidimensionnelles de Textes et de Questionneires*, IRaMuTeQ, 0.7 Alpha 2), a Descending Hierarchical Classification (DHC) and a Similitude Analysis.

Based on the results of the analyses by the experts, the app was reformulated, and the pre-final 1.0 version, to be applied in the pilot test, was reached. The pilot test was carried out to evaluate the perception of the target population of the app with regard to the clarity of the content of the version obtained in the previous stage. A convenience sample was formed, including 20 Portuguese parents who knew how to read and write, had children in the NU and wanted to participate in the study. They were asked to classify each item of the app in a dichotomous scale (as clear or not clear), providing suggestions to make the language clearer. The author of the QCP-NICU was involved in all stages of the study, so her opinion could be found on the precision of the translation when compared with the original. Her opinion was positive.

Data collection started after the study was approved by the Research Ethics Committee in Health from the hospital, on 2019/07/03, under number E. E909519. All collaborators in the study, specifically, the translators, experts, and parents, accepted participation by signing the Free and Informed Consent Form.

RESULTS

Comparison of translations and back translations

In stages 2 and 4, all sentences were checked, to reflect their meaning in a more accurate way. There were only minor discrepancies, related to literal translations and technical terms, that were corrected with the consensus of the participants. Professional classifications that are not adequate for Portuguese NUs were removed. Names of dimensions and categories were also changed to make them briefer (e.g.: substituting the titles of dimensions: "My pain and stress" by "Pain and stress"; "My family" by "Family"; and "My position and mobilization" by "Positioning and mobility").

Analysis of expert evaluation

From the 20 experts, 10 were nurses, who worked as specialist nurses, and 10 were physicians, who had neonatology as their sub-specialty or had experience in this field. Regarding the Content Validity Ratio (CVR), from the 42 items in the app that were analyzed by the 20 experts, 38 had positive CVR values, from 0 to 0.99. Concerning the table of minimal values of acceptance for CVR, we have found that, for the 20 experts, the lowest CVR necessary was 0.42⁽²³⁾. 35 items were found to be in accordance with this, representing 83%.

In turn, the lexicographical analysis of the text *corpus* formed by the transcription of the suggestions of the experts included 20 texts, organized mono-thematically, in a single file, in the software *Apache OpenOffice*. Each was separated by a command line and characterized according to the variables "participant" (p) and "health professional" (ps1-physician, ps2- nurse) (E.g.: **** *p_01 *ps_1). After a careful review of the text *corpus*, the document was recorded as a text document with a codification of characters in the UTF-8 (*Unicode Transformation Format 8-bit code units*). 30 text segments from the 37 in the *corpus* were kept, corresponding to 81.08% of the segments kept for the creation of four classes, resulting from partitions in the text. This result indicates a good consistency and that the content submitted to this type of analysis is adequate (25). 399 words appeared 1213 times, with a mean frequency of 32.78 words for each form. The cutoff point used to include words in the classes of the dendrogram was 0.66, and its association with the class they belonged to was $\chi^2 \ge 3.84$. These values were defined by a 95% significance level (25), with a mean margin of error of 5%.

In the dendrogram, the *corpus* was divided in two *sub-corpora*, separating classes 4 and 3 from classes 2 and 1. The interpretation of each class and the data analysis were carried out according to the knowledge about the content of the app. To visualize these classes better, an organizational chart was elaborated, with a list of the words from each class generated using the chi-squared test, as shown in Figure 2.

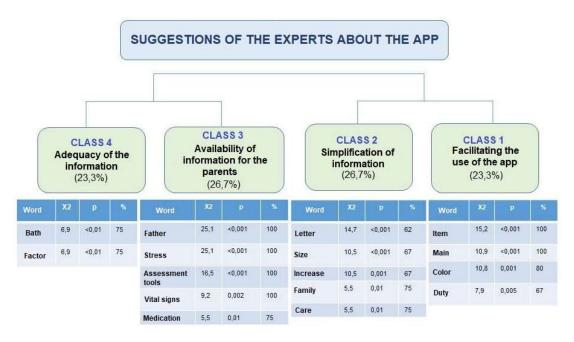


Figure 2. Classes that make up the textual corpus dendrogram.

The association of the words with the class they belonged two always had the value of $\chi^2 \ge 3.84$ with p<0.05).

Class 4 represents 23.3% of the total *corpus* analyzed and expresses the suggestions related with the *Adequacy of the information*. This class is formed by the words Bath and Factor, with *p value* below 0.01. Three experts (p02, p03, and p19) suggested adapting *what is prescribed* to *what is done in practice* (p03) regarding the technique of baths while bandaged, described in the dimension Baby skin, in the sub-category Bath. The sub-category Factors, from the dimension Pain and stress, also were mentioned by

three experts (p01, p06, p07), who found the information in it to be *overlapping* (p01) and its description *exhaustive* (p07). Another suggestion was *to write the words "cvu"* and "lau" in full (p06).

Class 3, called Availability of information for the parents included 26.7% of the text segments analyzed. It included the words Father, Stress, Evaluation instruments, Vital signs, and Medication, with p value below 0.01. In the analysis, it was found that seven experts, mostly nurses, stated that the information in the sub-categories Evaluation instruments, Vital Signs, and Medication as too much (p14, p20), excessive (p16, p17), detailed (p01), comprehensive (p18), and complex (p08) for the parents. The experts showed preoccupation with the information, since it can be a source of stress (p01) or can provoke (p17), generate (p18, p20), and cause (p14, p16) stress in the parents. The subcategory Evaluation tools was the most mentioned in this aspect, being addressed by five experts, three nurses and two physicians. One nurse mentioned that it is not necessary for parents to know how many scales to assess pain there are (p16), and one physician suggested that it is enought to inform only that there are scales for the assessment. The subcategory Medication was mentioned by three nurses (p14, p17, p20), while the subcategory Vital signs was mentioned by one physician (p01) and two nurses (p17 and p20), one of whom (p20) mentioned, specifically, the information in the vital signs table.

In class 2, called Simplification of information for the parents, which also represented 26.7% of the content analyzed, the words Letter, Size, Increase, Family, and Care were emphasized, with p value below 0.01. Eight experts, three physicians (p6, p9, p10) and five nurses (p13, p14, p16, p17, p18) highlighted the need to increase the size of the letters in the app to make reading easier (p17). The category People, from dimension A, My first home, was mentioned by four experts. Two considered the information too excessive (p13, p17), one warned about the need to correct the description of the competences of the neonatologist and the radiography technician (p06), and another suggested to reevaluate the pertinence of so many professionals and adapt to the Portuguese reality (p16). Nurse (p13) also suggested to put images instead of information. Also, in the category, What is around me, suggestions were given to simplify the information (p09, p14, and p18). Three experts, two nurses (p14, p18) and one physician (p09) mentioned the questionnaires in the category Caring, from the dimension Family. They considered that they should be only informative (p09) and be applied by professionals with therapeutic goals (p18), and that they should be filled in with professional support(p14).

Class 1, called *Facilitating the use of the app* included 23.3% of the text segments evaluated, using the words Item, Main, Color, and Duty, with *p value* below 0.01. The experts suggested to *use colors* (p2, p3), *diversify colors*, (p15, p02, p03) and *differentiate by collors* (p01) the items of the app, especially the main ones (p01, p03, p11). These changes would make it possible to *increase interest* (p15), facilitate *navigation* (p03) and *the handling of information* (p01). Still in this scope, the *power to move the images back and forth by touching the screen* (p02) and improving the explanation about how to explore the app in the dimension Baby skin (p13). In general, one nurse considered that there were *too many content ramifications* (p15), and two physicians stated that the information was *useful but too detailed* (p01, p08), especially in the category What is around me, from the dimension My first home(p01).

The Similitude Analysis, based on the graph theory, synthesizes the lexical content found using the classes presented, according to Figure 3.

father

replace
stress
ventilation_equipment

Subcatg

bath

text
pain_stress
baby skin
information
cimension
catg
word

app
facilitate
too much
letter size
color

duty
increase

Figure 3. Similitude analysis of the text corpus

The size of the letters and the thickness of the traces that connect them show the relevance to understand the phenomenon being studied. It has been found that Dimension is the word that stands out the most and presents the highest correlation with the words App, Category, Subcategory, Information, First home, Pain, and Stress. The words Size and Letters come from the word app, with a significant expression, while the words Duty, Color, Item, and Facilitate are expressed in minor sizes. Associated with the word Subcategory are the words Father, Stress, Replace, and Ventilation equipment. The words Information, Pain and stress, and Category have no ramifications. Using these connections, it can be inferred that the suggestions of the experts are essentially inherent to the dimension My first home, to the category Pain and stress, and to the questions about the information of the parents and usability of the app.

Pilot test of the translated app

In this stage, all participants (n=20) mentioned that the items that formed the app were clear. As a suggestion for its improvement, two parents found it useful to make available written instructions on how to go from one slide to another, since they had doubts about it. In general, there were no difficulties that suggested the final translation should be altered. The final Portuguese version of the QCP-NICU mobile application received the name of Quantum a Cuidar dos Pais — Unidade de Neonatologia (QCP-UN).

DISCUSSION

This study was the translation and transcultural adaptation of the app QCP-NICU for the Portuguese context. The cultural translation and adaptation is important because it provides more than a simple literal translation (22). However, to the extent of our knowledge, there are no specific directives about how to conduct this process in a reliable and objective way for apps. Therefore, the stages of this study included the

methodological directives used in transcultural translation and adaptations of other type of health instrument.

In general, the process as a whole was balanced, with no need for major changes to most items. The stages related to translation and back translation had no incidents. The discrepancies found were minor and only related to literal translation and technical terms. Since they affected meaning and understanding, the choice to correct these discrepancies was a consensus. The names of items and categories were also changed as to make them more synthetic and adaptable to the interface of the app. The analysis of the app by the experts showed a satisfactory content analysis, where 83.33% of the items in the app had CVR values above the minimum required (CVR=0.42) for the 20 experts. The suggestions from the experts were essentially focused on the items with CVR values below the prescribed and refer to the items Pain and stress and My first home.

The lexicographical analysis of the text *corpus* with the suggestions of the experts made it possible to find that these are, mostly, related to the type of information made available to the parents, and it was necessary to simplify this information and adapt it either to the parents or to the reality of the practice of care. These suggestions are in accordance with the results of other studies, specifically, with a descriptive study carried out in the USA, which showed changes in the preoccupations, focus, and learning process of parents during NU hospitalizations, warning about the need to adapt the information to the learning stage in which the parents were. In the acute stage, the parents wanted more information than they received from health professionals about the health condition of their children and their understanding of technical terms and coping strategies, while, in the recovery and post-discharge stages, the focus was on the health condition of the child, the care, and the coping strategies (26). Other studies corroborated the need for the information to be adequate to the level of understanding of the parents (27), since clinical terminology can be an obstacle to the involvement of parents in the care for their children (7).

Regarding the information made available to the parents, the experts emphasized information related to the pain assessment instruments, to the vital signs and to the therapy, since they believe it is excessive, complex, and a potential source of stress to the parents. It was also found, via another research, that the parents experience stress and anxiety during NU hospitalizations that prejudice the understanding and assimilation of the information provided by the professionals ⁽⁶⁾. These results reiterate the need to guarantee the principle of shared information implicit in the CFF philosophy, which involves transmitting information in a manner that can be understood by the parents ⁽⁴⁾.

Finally, the experts also made suggestions related to facilitating the use of the app, which are in accordance with the value of usability, recognized as essential in the development and implementation of any successful app ⁽²⁸⁾. The content of the apps was reviewed based on the suggestions of experts and submitted to pilot tests. The participants in the test (n=20) considered that all items in the app were clear. Two participants suggested that written instructions about how to go from one slide to the next should be made available. All suggestions were presented and accepted by the author. However, those related to improving the usability of the app, especially regarding the size of the letters and the use of more varied colors, were not implemented, due to issues inherent to the interface of the app itself.

This was the first study carried out with this app in this context, which makes comparisons impossible. To carry this study out, it was decided that it would follow a specific methodology for apps; however, we could not find any others. Therefore, these two aspects may be considered as limitations of this study. Additionally, we suggest further studies to be made, using more varied and larger samples, to represent larger portions of the Portuguese culture and other Portuguese-speaking countries. We also suggest studies to evaluate the usability, acceptance, and usefulness of the app by parents with children hospitalized in NUs.

As for practical implications, the Portuguese version of the QCP-NICU app can be used as an educational resource to facilitate the practices of education in health in the NU, valuing the role of the nurse and contributing for the increase in the HL of the parents in this context.

CONCLUSIONS

This study was a cultural translation and adaptation into Portuguese of the app QCP-NICU, which is a useful resource, complementary to health education for parents in the NU, based on scientific evidences. The use of the app by the nurse enables the planning of organized interventions of education in health, facilitates making this information available for the parents and providing a uniform distribution of information. It also makes it possible for parents to have a more active role in this process, assimilating the information at their own pace and consulting it whenever necessary, contributing for a scientifically based decision making regarding the care for their children.

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