

TRANSLATION AND CULTURAL ADAPTATION OF THE FAMILY CENTERED CARE ASSESSMENT SCALE (FCCAS) FOR FINNISH PEDIATRIC NURSING

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Abstract

Purpose: The purpose of this study was to translate and culturally adapt the Family Centered Care Assessment Scale (FCCAS) to evaluate family-centered care in the context of Finnish pediatric nursing.

Design and Methods: The translation and cultural adaptation were done according guidelines of International Society for Pharmacoeconomics and Outcomes (ISPOR), which constitute a systematic process including ten phases. The presented research included cognitive interviews conducted with the end user of the scale: parents of hospitalized children.

Results: The FCCAS was successfully translated and culturally adapted to the Finnish context. Translational, clinical and parental expertise were used to develop the scale. Conceptual equivalence was achieved in the translation. In the cultural adaptation, some of the items were modified based on experts' assessments to make them comprehensible and appropriate to the Finnish culture. The scale showed good evidence of content. Reporting of the study adheres to the COSMIN checklist.

Conclusions: Combining ISPOR guidelines and cognitive interviews are recommended to use in the translation and cultural adaptation process. Nursing staff and parents' involvement and awareness of family-centered care have been concretized. Systematic translation and cultural adaptation have prepared a Finnish version of the scale for psychometric testing.

Practice implications: The study outlines how rigorous methodological approaches can be applied to the translation and cultural adaptation of a measurement tool. The developed scale includes items which comprehensively cover family-centered care characteristics. In following study, it will be possible to evaluate the extent to which family-centered care is implemented in Finnish pediatric nursing.

Keywords: cultural adaptation, family-centered care, scale development, translation, cognitive interview

Introduction

Family-centered care (FCC) is a key nursing principle ([Harrison, 2010](#)), and commonly used in pediatric care worldwide because it is considered the optimal way to provide care to hospitalized children and involves parents in the treatment ([Harrison, 2010](#); [O'Connor et. al., 2019](#); [Shields et. al., 2012](#); [Smith, 2018](#)). From the FCC perspective families and health care professionals form a partnership ([Coyne et. al., 2018](#); [Dennis et. al., 2016](#); [Harrison, 2010](#); [Kuo et. al., 2012](#); [Smith, 2018](#)), characterized by respect and trust ([O'Connor et al., 2019](#)).

The concept of the FCC has been defined in several studies. For example, FCC can be defined as a philosophy of care where the family is central to the patient's life seeing the patient in the context of his/her unique family, and supports family members in their role as priority caretakers ([Smith, 2018](#)). FCC philosophy posits that parents are experts in the care of their own child, while health care professionals serve an advisory role. ([Bruce & Ritchie, 1997](#); [Coyne et al., 2018](#)). The aim and characteristic of the partnership is shared responsibility for the care of a hospitalized child ([Mikkelsen & Frederiksen, 2011](#)). One of the most significant components of FCC is communication and negotiation between the family and health care professionals ([Coyne et al., 2018](#); [Kuo et al., 2012](#); [Mikkelsen & Frederiksen, 2011](#); [Smith, 2018](#)). Open and honest communication is associated with additional FCC characteristics, e.g., information sharing and shared decision-making ([Coyne et al., 2018](#); [O'Connor et al., 2019](#)) and support of the family ([Mikkelsen & Frederiksen, 2011](#); [Smith, 2018](#)). In FCC it is also essential to continuously evaluate the care ([Smith, 2018](#)). In addition, FCC should be culturally responsive ([Coyne et al., 2018](#); [Smith, 2018](#)).

The implementation of FCC culture enables individualized and flexible care ([Smith, 2018](#)), which strengthens the parent's role ([Watts et al. 2014](#)) and leads to a high degree of parental satisfaction ([Shields et al. 2012](#)) and empowerment ([Mikkelsen & Frederiksen, 2011](#)). Previous research has raised the following benefits FCC: reduced parental anxiety ([Coyne et al., 2018](#); [Curtis et al., 2016](#)) better communication between family and professionals ([Curtis et al., 2018](#)); and cost-effective care ([Harrison, 2010](#); [Shields et al., 2012](#)). On the other hand, families have also reported negative experiences from FCC, e.g., experiencing stress or feeling like a burden related to caring for the child ([Mikkelsen & Frederiksen, 2011](#)). It is important to note that there is still a limited knowledge base concerning how FCC affects children, families, and health care professionals. ([Shields et al., 2012](#); [O'Connor et al., 2019](#)).

FCC can be difficult to implement in pediatric nursing ([Harrison, 2010](#); [Kuo et al., 2012](#); [O'Connor et al., 2019](#); [Smith, 2018](#)), with the most common barriers including ambiguities in parental and professional roles ([Butler et al., 2014](#); [Mikkelsen & Frederiksen, 2011](#); [Prasopkittikun et al., 2020](#)), an unsupportive organizational culture ([Prasopkittikun et al., 2020](#)), and differences between various definitions of FCC ([O'Connor et al., 2019](#)). A clear understanding of FCC, along with the education of professionals, promote FCC implementation ([Akkus et al., 2020](#); [O'Connor et al., 2019](#)). Health care professionals then have a responsibility to evaluate the success of FCC implementation by developing validated measurement ([Kuo et al., 2012](#)).

Various measures have been developed to evaluate the implementation of FCC since the 1990s ([Arslan et al., 2019](#); [Bruce & Ritchie, 1997](#); [Curley et al., 2013](#); [King et al., 2004](#); [Miles et al., 1999](#); [Shields & Tanner, 2004](#)) and, subsequently, ensure high quality pediatric care ([Lindly et al., 2017](#)). The evolution of FCC coincides with extensive cultural and societal changes ([O'Connor et al., 2019](#)). Although FCC is currently used worldwide, health care professionals should remember to take into account cultural diversity when assessing the extent to which the FCC philosophy is applied in the clinical environment ([Aftyka et al., 2017](#); [O'Connor et al., 2019](#)). It should be noted that the application of FCC should only be assessed through a valid and reliable measurement tool. Hence, the existing measurement tool must undergo systematic translation and cultural adaptation ([Sousa & Rojjanasrirat 2011](#); [Wild et al., 2005](#)) if the application of FCC is to be investigated in the other cultural context of pediatric nursing.

The latest developed scale published by [Arslan et al. \(2019\)](#) is the Family Centered Care Assessment Scale (FCCAS) that evaluates FCC from the parents of hospitalized children. The FCCAS includes all of the FCC characteristics which have been described as essential in recent studies ([Coyne et al., 2018](#); [O'Connor et al., 2019](#); [Smith, 2018](#)). Important in the study is the persistence of the assessment method over time ([DeVellis, 2017](#)): the content of the assessment method must be consistent with the current FCC concept. It is not appropriate to evaluate the implementation of the FCC on a scale that is not based on the current FCC definition and characteristics. Furthermore, scales which are as detailed as the FCCAS enable researchers to recognize strengths and weaknesses in the measured phenomenon, which will be important to further developing the FCC philosophy ([Arslan et al., 2019](#); [Coyne et al., 2018](#)). Additionally, the FCCAS is not limited to the parents of children of a certain age, but applicable to all the family members of a hospitalized child ([Arslan et al., 2019](#)).

Translation and cultural validation are necessary whenever an international scale is applied to a new context ([Polit & Beck, 2017](#); [Wild et al., 2005](#)). In Finland, FCC is central to pediatric nursing, but there is currently no valid scale for evaluating FCC in this context. There is also a need for a valid scale in order to make comparisons at national level. Thus, this study aimed to translate and culturally adapt the FCCAS to the Finnish context to evaluate parent experiences of FCC in pediatric nursing.

Methods

Design

The translation and cultural adaptation of the FCCAS was conducted according to ISPOR guidelines ([Wild et al., 2005](#)). The ISPOR guidelines were chosen because they constitute a systematic process including ten distinct phases ([Baker et. al., 2010](#); [Wild et al., 2005](#)).

In this study, cognitive debriefing was added to the end of phases 9 (cognitive debriefing II) and 10 (review of cognitive debriefing results and finalization). Phase 9 includes parents' assessments of the quality of the scale as well as cognitive interviews. Cognitive interviewing was used because it allowed the researchers to follow the respondents' thought processes and gain insight into the comprehensibility of the scale's items (DeVellis, 2017; Miller & Ryan, 2014). Cognitive interviewing has been recommended for involving patients in scale development and cross-cultural validation because it increases the usability and content validity of the scale ([Barr & Elwyn, 2015](#); [Kelly et. al., 2016](#); [Patrick et. al., 2011](#); [WHO, 2020](#)) and strengthens parental involvement and philosophy of FCC development of the scale ([Kuo et al., 2012](#)). The research phases were conducted from February to November 2020, with the distinct phases presented in Figure 1.

Insert Figure 1.

The original scale

The FCCAS was developed to evaluate FCC from the perspective of parents of hospitalized children. This scale includes 21 -items distributed among the scale's three factors: support (ten items); collaboration (eight items); and respect (three items). Parents grade each item using a five-point Likert scale (1=never, 2=rarely, 3=sometimes, 4=often, 5=always). The FCCAS has been shown acceptable psychometric properties for evaluating FCC in pediatric clinics, with the exception of neonatal care units ([Arslan et al., 2019](#)) demonstrating a good internal consistency coefficient (Cronbach's Alpha 0.94 for the total scale and >0.70 for each of the subscales). The FCCAS was reported in English in the original version. ([Arslan et al., 2019](#)).

Phases 1-6: The translation process

Preparation

The preparation phase included requesting permission to use and translate the scale from the original developers. Certified translators were invited to participate in the study. Three different expert panels were used in different phases in the process. Respondents of expert panels 1 and 2 (pediatric nurses and pediatricians) were invited to participate in the study. The respondents of the expert panel 3 (parents) were recruited later.

Forward translation

Two professional translators independently translated the scale into Finnish. As recommended, both were native speakers of Finnish ([Wild et al., 2005](#)). This resulted in two independent translations of the FCCAS (T1 and T2).

Reconciliation phase

The research group (MU, MR, OK, TP) discussed how to merge the forward translations T1 and T2 into a single forward translation. Creating a single forward translation would result in a scale which includes as few misinterpretations as possible ([Wild et al. 2005](#)). Translations that best reflected the original version and were the most suitable for Finnish nursing culture were chosen when creating the single forward translation. In case of discrepancies between the translations, the more appropriate option was chosen or the items of both translations were modified.

Back translation

A translator who was not familiar with the scale translated the scale back from Finnish to English. As recommended, this translator was a native English speaker ([Wild et al., 2005](#)). This phase increased the quality of scale development as the researchers were able to determine whether any of the original content of the scale had been lost during the back translation process ([Souza & Rojjanasrirat, 2011](#); [WHO, 2020](#); [Wild et al., 2005](#)).

Back translation review

Expert panel 1 (n=4) evaluated the original and back translated version of the scale. The evaluation form included the original and translated items side-by-side. For each item, the experts were asked to respond to the question “Does the translated version correspond in content to the original?” as either yes or no. They were also afforded the opportunity to expand on their response in an open-ended comments section. Expert panel 1 consisted of two pediatricians and

two pediatric nurses. Experts were chosen by the researcher (MU) based on the following inclusion criteria: wide expertise and experience (minimum ten years in pediatric ward) on FCC and excellent knowledge of Finnish and English. Pediatricians were included in expert panel 1 to add an additional perspective to the scale development process. The evaluations of expert panel 1 respondents were then combined into a table to enable comparisons.

Harmonization

The research group discussed the evaluations by expert panel 1 to detect and correct any differences between the two forward translations. These discussions yielded one single Finnish forward translation of the scale. Following harmonization, approval for the back translation was sought from the developers of the original scale. They approved the back-translated version of the FCCAS.

Phases 7-12: The cultural adaptation

Cognitive debriefing I

Expert panel 2 evaluated the content and usability of the scale. Expert panel 2 consisted of seven nurses and three parents (n=10). The nurses worked in pediatric wards (neurology, oncology, surgery, pediatric intensive care, neonatal intensive care) of a university hospital in Finland. The inclusion criterion for nurses was wide expertise in the FCC philosophy, which was evaluated by their charge nurse. Parents were chosen at the discretion of the researcher (MU). All the experts emphasized that they had experienced the hospitalization of a child at some point during the last three years and were able to assess the scale. Experts evaluated items with a four-point scale: 1 (not relevant at all); 2 (somewhat relevant); 3 (quite relevant); and 4 (highly relevant). The evaluations were analyzed with the Content Validity Index for Items (I-CVI) and Content Validity Index for Scales (S-CVI/Ave). The CVI is a widely used method for evaluating content validity (Polit, Beck, & Owen 2007). For sufficient validity, I-CVI should exceed 0.78 and S-CVI/Ave should be 0.90 or higher if there are more than six experts (Polit & Beck, 2006; Polit et al., 2007). In this study, the experts graded the validity of the whole scale from 1-10 and were also able to write general remarks in the comments section. The experts could additionally specify if the scale should include further items relevant to FCC that are currently missing. Expert panel 2 had approximately one month to complete.

Review of cognitive debriefing I results

The results from the evaluation by expert panel 2 were used to construct a table, after which the necessary changes were made to the scale. The changes were based on the expert panel assessment and a discussion between the research group members. Some modifications were made to the scale, which progressed to the cultural adaptation.

Cognitive debriefing II

Expert panel 3 (n=16) evaluated the content and usability of the scale. The inclusion criteria were: being the parent of a child who had been hospitalized for at least 24 hours; and being able to speak, read, and write in the Finnish language. The expert panel 3 included six parent experts whose children had been admitted to different pediatric wards (general medical, neurology, oncology, surgery, pediatric intensive care, neonatal intensive care) at one Finnish university hospital. Eligible parent experts received an information form about the study, on the basis of which they decided whether or not to participate. Parent experts were allowed to choose whether they wanted to participate only in the written assessment of the scale or also in the interviews. A total of 16 parent experts evaluated the scale, with (n=7) participating cognitive interviews. There were six cognitive interviews, with one involving both parents.

During the assessment, parent experts were asked to answer whether each item was understandable using either yes or no. They could also add comments for each item. Respondents kept track of the time when they started and stopped filling in the scale. Finally, they rated the scale numerically from 1 (worst value) to 10 (best value) and wrote open comments about the overall evaluation of the scale, its comprehensibility, and its suitability for practice.

During the cognitive interviews, the parents were encouraged to think aloud and comment spontaneously. The interviewer made sure to tell the respondents that the purpose of the interview is to evaluate the scale, not the parent as a respondent. An interview guide was developed, with the parents initially asked to describe their overall impression of the whole scale. Next, each item was reviewed, with the interviewer asking the parent "How did you arrive at that answer?". The parents were also asked to evaluate the comprehensibility and necessity of each item, and were afforded the opportunity to share suggestions for how to develop the item. Finally, the parent was asked if some area of FCC was missing from the scale or if they had additional general comments. Interviews were carried out as soon as possible, during the same day, after the assessment of the scale. The interviews, which lasted between 20 and 50 minutes, were conducted by one researcher (MU).

The data were analyzed according to the process described by Miller et al. (2014): conducting; summarizing; comparing; and concluding. The recorded interviews were transcribed word for word. The material was read through several times before the researcher selected specific sentences that were relevant to the research phenomenon. These selected sentences were then compiled in a table to aid comparisons. The sentences were organized based on whether they described an item, comprehensibility, necessity, or general comments. Data from the initial expert panel evaluation of the scale were also added to the table.

Review of cognitive debriefing II results and finalization

Necessary changes to the scale were made based on the previous phase. The changes were based on the assessment by expert panel 3 and a discussion between research group members.

Proofreading and final report

The final quality-control step of the research was the proofreading of the scale, after which any errors were corrected. The reporting of the translation and cultural adaptation covered the applied methodology, including detailed descriptions all of the phases (Wild, et al. 2005). Reporting of the study adheres to the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) cross-cultural validity checklist (See Supplementary File 1). (Mokkink et. al., 2010).

Ethical considerations

Approval to conduct the study was obtained from the Northern Ostrobothnia Hospital District (number 26/2020). All experts received written information about the study. Respondents from expert panels 1 and 2 signed their consent to participate when completing the evaluation form. Parents in expert panel 3 gave their written consent separately. Expert panel participants were informed that all research-related files were to be considered confidential, they could withdraw at any time, and their participation was voluntary. The study followed national ethical guidelines (TENK, 2019), the Declaration of Helsinki (WMA, 2013) and legislation regarding personal data (GDPR, 2018).

Results

Reconciliation after forward translation

The two Finnish translations of the FCCAS had all three sections and five items with identical translations. These were considered appropriate translations, and, as such, not edited. The research group evaluated that T1 was preferable in nine items while T2 was preferable in two items. In both translations, four items were modified. In two items, the word describing a child's state of health was modified to a term that is more commonly used in Finnish pediatric nursing.

Back translation review and harmonization

After back translation, two items and two subscales were identical to the original scale. The title, one subscale and 19 items of the back translation differed from the original version of the scale. Expert panel 1 evaluated that there were only five points (title, subscale, three items) at which the back translated version of the scale did not fully correspond with the original version (See Supplementary File 2). During the harmonization phase, the research group analyzed expert panel 1 evaluations to construct a final back translation. The developers of the original scale accepted the final back translation without modifications.

Cognitive debriefing I

The I-CVI values resulting from the assessment of item content and usability were acceptable for 20 out of 21 scale items (Table 1). The average S-CVI value, which describes the entire scale, was 0.95.

Insert Table 1

The provided open-ended comments revealed that two items were assessed as highly relevant, but also as somewhat extensive and unclear. The item describing the nurse's awareness of parents' needs was evaluated as inconsistent because it did not specify whether the nurse had enquired about the child's needs. One item was evaluated as not relevant. The open-ended comments also revealed that asking parents for consent before an intervention is not suitable for Finnish nursing care. In contrast, explaining and justifying the interventions taken for the child was considered to be very important. A nurse's support to other visiting family members was evaluated as relevant to FCC, with the exception of pediatric intensive care, as visits by family members other than the parents are not permitted. Moreover, three items were found to have suggestive wording, and the experts felt that more general expressions would be better.

One expert evaluated that items concerning a nurse's respect of privacy and confidentiality, along with calling a child by their name, were not related to the FCC philosophy.

The experts could also provide open-ended comments about the scale in its entirety. Several experts noted that FCC involves other professional groups than just nurses; as such, the current scale does not sufficiently frame FCC as a multi-professional practice. Some experts suggested changing the word "nurse" to "nursing staff" to allow a wider assessment of FCC. Other comments concerned whether the scale is suitable to all of the age groups which are treated in pediatric wards. Experts also noted that items about parental coping and family life situation (e.g., different forms of family) were missing. Two experts evaluated that the scale is missing an item about the presence of parents with their child (e.g., an overnight stay). Overall the presented version of FCCAS was evaluated to be comprehensive and clear, and to holistically cover the FCC philosophy. The mean score for the comprehensibility and suitability of the scale, rated from 1-10, was 8.5.

Review of cognitive debriefing I results

Necessary modifications were made to the scale after the research group reviewed the evaluations by expert panel 2 (See Supplementary File 3). There were nine items that remained unchanged. The wording of eight items was changed to make them more comprehensible. Some of these items were also reworded to represent the whole family in accordance with the FCC philosophy. The researchers felt that existing items already covered parental coping and various family life situations, which some experts felt were not completely represented in the scale. One item had initially included an example within parentheses, but this example was removed because the item could be understood without it. One item, which concerned the nurse calling the child by their name, was completely reformatted to be suitable to the Finnish nursing culture.

The order of the items was modified so that two items were transferred from the support subscale to the respect subscale and one item from the support subscale to the collaboration subscale. The item which was assessed as not relevant (I-CVI 0.40) by the expert panel was removed completely. The presence of parents with their child was captured by new item ("The nurse supports my participation in the child's care at all times of the day (e.g. the opportunity to overnight stay with my child in the hospital)"), which was added to the support subscale. The item was added based on the FCC philosophy and the fundamental rights of children, both of which were discussed by the expert panel. The word "nurse" was retained in the items.

Cognitive debriefing II

The second round of cognitive debriefing included evaluations by expert panel 3, which consisted of parent experts. Results from the scale assessment (n=10) and cognitive interviews (n=7) are reported separately.

In the scale assessments, the parent experts responded to each item. According to the expert panel 3 assessments, 16 of the 21 items were understandable. The remaining five items were less comprehensible, with one or two parent experts having given a negative response to item comprehensibility. The open-ended comments provided more insight into the comprehensibility of these items. For two items, some of the parent experts felt that adding more answer options (e.g., “I can't say”) would make them easier to answer. These items were related to the nurse’s awareness of the family’s life situation and respect for the family’s culture. The item which concerned whether the child was treated according to his or her age and level of development was evaluated as challenging to answer for parents with newborns.

In general, the open-ended comments concerning the scale in its entirety described the scale as comprehensible. Challenges in responding to some of the items were related to child being a newborn, differences between ordinary pediatric wards and the intensive care unit, differences in the way nurses work, and situations in which other family members are a long distance from the hospital. In one evaluation reported that the scale was missing items related to how multilingual families get up-to-date information about the status of their child.

The cognitive interviews revealed the thought processes related to the situations and interventions experienced in the care of hospitalized children; parent experts used many examples of the care of their child when explaining how they assessed each item (See Supplementary File 4). The thought processes of various parent experts were similar for items which they had evaluated as comprehensive. However, one item, which was related to whether the child was treated according to his or her age and level of development, raised irrelevant and conflicting responses in comparison to what the item was intended to measure from the FCC perspective. Some respondents felt that it would be challenging to answer the question if the child is a newborn. The thought processes captured for the other items were strongly related to the content of the items and the FCC philosophy.

The cognitive interviews revealed that the parent experts felt that ten items were understandable, but experienced misunderstandings in eleven items. Items which included the word “life situation” were reported to be unclear. Some parent experts felt that other items (e.g., “The nurse tells me about the procedures that will be done to my child”) were difficult to understand because the parent experts were uncertain as to whether the item referred to only procedures conducted by the nurses. This was particularly pronounced for children who received care from multi-professional teams. Items, which asked about the feelings that nurse evoked in parents (e.g., “The nurse makes me feel like I'm taking good care of my child”, “The nurse makes me feel like I can influence my child's care.”) were assessed as nonspecific by some parent experts. Moreover, items related to how the nurse perceives the parent’s role in the health team were evaluated as difficult to answer because the parent cannot be sure of the nurse’s opinion. One parent expert reported that two items related to parental influence in a child’s care were difficult to answer because they did not recognize situations in which they could influence their child’s care. The wording of another item related to how nurses take into account the whole family was reported to be nonspecific. When discussing an item related to nurses respecting a child's privacy and confidentiality, one parent expert did not know what “confidentiality” means, while another felt that they cannot evaluate a nurse’s obligation of confidentiality. As was the case in the scale assessments, the item related to treating child according to his or her age and level of development was evaluated as difficult to answer for parents with newborns. It should be noted that this item was evaluated as understandable in cases in which the child was not a newborn.

The expert panel 3 unanimously agreed that ten of the items were necessary. The most common reason as to why an item was deemed unnecessary was that it was unclear. Moreover, one of the parent experts felt that two of the items were not so important when the child is an adolescent. These items were related to caring for a child (e.g. “The nurse makes me feel like I'm taking good care of my child”). On the other hand, other parents of adolescents felt that these two items were important. The parent expert evaluations revealed that two items were not so important when the child is a newborn. The first item related to treating was the child according to his or her age and level of development, while the second item was “The nurse asks for my opinion about my child’s state of health”. The latter item was evaluated as completely understandable but rarely realized in nursing care. Furthermore, the parent experts felt that would be challenging to respond to this item if the newborn had been in the hospital all the time.

Only half of the parent experts considered the item about visits by other family members to be necessary. The influence of the Covid-19 –pandemic on daily life became clear in the interviews, and clearly influenced the evaluation of the

necessity of this item. The transcript from one interview revealed a certain degree of overlap between items related to obtaining information about children.

In general, the parent experts evaluated the scale as comprehensible and easy to use. Difficulties in understanding the scale were mainly related to the child being a newborn or differences in the way that nurses work. Some parent experts also expressed that certain items may be difficult to answer on behalf of the whole family. Situations in which a child is cared for by a multi-professional team also made answering certain items difficult because the subject was “the nurse”. Parent experts were positive about using the scale and appreciated the many benefits of its implication, namely, moving towards consistent care, development of the unit, and getting feedback from families. The FCC philosophy was clearly evident in the scale.

The parent experts (n=16) took an average of nine minutes (range: 4-20min) to fill in the scale. The average overall rating (scale 0-10) of the scale was 8.6.

Review of cognitive debriefing II results and finalization

After cognitive debriefing II, 11 items did not require modifications. In nine items, the need for change was assessed, while two items required rewording. Changes were made to three items to increase the accuracy of the item. Parts of two items were deleted to improve comprehensibility. Furthermore, an item related to how the nurse sees the parent as part of their child’s care, was changed so that it evaluates the nurse’s sense of how important parenting is in the health team. This modified item follows the original scale better. Two items were considerably modified to improve their comprehensibility and ensure that all age groups are taken into account. Examples of changes are shown in Table 2. Even though several parents did not consider the item linked to visits from other family members necessary due to the current Covid-19 -situation, the item was nevertheless retained as it is essential to the FCC philosophy. The lack of family member visits due to the current situation or living far from the hospital, as well as situations in which the parent is separated from the child, served as a justification for the inclusion of the item in the scale, which takes into account the use of remote connections. Items related to what emotions the nurses evoke in parent remained unchanged because the content of these items could have changed too much if the items had been changed.

(Insert Table 2)

A short sentence was added to the beginning of the scale to describe the purpose of the scale, i.e., assess the realization of FCC by nurses although other professionals also care for the children. This sentence was added to clarify the purpose of the scale and reduce any potential for misunderstandings.

Proofreading and reporting

The research group analyzed and compared how the final scale compared to the original. The grammar of the scale was checked, and any errors were corrected. This manuscript has described the translation and cultural adaptation of FCCAS in sufficient detail.

Discussion

Combining the ISPOR method with cognitive interviews contribute to the quality of the translation and cultural adaptation of the FCCAS to the Finnish context, as well as increase the content validity of the scale (Barr & Elwyn, 2015; Kelly et al., 2016; Wild et al., 2005). The translation and cultural adaptation of the FCCAS was time-consuming and required careful planning, as has been reported in earlier studies (Kalfoss, 2019; Pudas-Tähkä et. al., 2014; Sousa & Rojjsarinat, 2011). The Finnish version of FCCAS includes FCC characteristics which have been evaluated throughout this process by three distinct expert panels: a total of nine items remained unchanged, while eleven items were modified. Furthermore, one item which was non-relevant for the Finnish nursing culture was removed. A further two items was added to the scale to increase the extent to which the FCC philosophy is reflected in the scale. Linguistic and cultural variation could be observed between the two version which may be an indication of how the concept of FCC translates across different cultures.

Translation yielded a scale that was conceptually equivalent to the original scale, while cultural adaptation was successful based on the assessments of several expert panels, i.e., the scale items comprehensively reflected the FCC philosophy. The translation and clinical expertise complemented one another when avoiding misinterpretations is possible.

The participation of both pediatricians and pediatric nurses in the back translation review introduced additional perspectives to scale development. The evaluations of experts representing diverse pediatric wards confirmed that the scale is applicable to a wide range of clinical settings. Neonatal intensive care unit nurses' evaluations demonstrated that the scale is applicable to all Finnish pediatric wards, although the original FCCAS scale was found to not be

appropriate to the neonatal intensive care unit ([Arslan et al., 2019](#)). On the other hand, a later phase revealed that most parents of newborns felt that some of the content of the scale was unclear. Nevertheless, they reported that the scale is quite clear and useful with a few modifications. The suitability of the scale to children of various age groups is an advantage in terms of the usability of the scale. The FCC philosophy does not report differential effects for various age groups. Instead, the realization of FCC enables individualized and flexible care, which applies to various age and patient groups ([Smith, 2018](#)).

Involving parents of hospitalized children was necessary to the cultural adaptation of the FCCAS because these parents are the end users of the scale ([WHO 2020](#)). The cognitive debriefing II included parents of children representing different age groups and who had admitted at various pediatric wards. Background data were not collected from parent experts because it was decided that this information would not be relevant to the development of the scale.

Parent experts raised issues that were not present in the nurses' evaluations, e.g., parental coping. Parents and nurses had similar opinions in certain cases, which led to the removal of non-relevant items. The method of cognitive interviewing provided evidence for the comprehensibility of various items by capturing the parents' thought processes ([Miller & Ryan, 2014](#)). Although the parent experts were quite content with the scale, cognitive debriefing II was needed, which proved that modifications to the scale were needed after cognitive debriefing I.

Experts in both cognitive debriefing phases evaluated that using only the term "nurse" in the items was a limitation of the scale because multi-professional teams are strongly involved in pediatric nursing and impact the quality of FCC ([Toivonen et. al., 2020](#)). Definition of FCC, rarely only consider nurses, but rather address all professionals involved in the care of a child ([Mikkelsen & Frederiksen, 2011](#); [O'Connor et al., 2019](#)). The term "nurse" was retained in the items because the researchers felt that parents' responses could be inconsistent if different professional groups of nursing staff work in different ways. Furthermore, if the scale will eventually be used to develop FCC, it will not be possible to influence more than one professional group. It should be stated that expert panel 2 was composed exclusively of nurses. A sentence was added to the beginning of the scale to prevent any misunderstandings that might distort a parent expert's responses to the items.

The cultural adaptation of the FCCAS yielded two new items that confirm the FCC philosophy as the basis of the scale. The first item is related to parent's presence with their child at all times of the day, which is associated with parental participation in the care of a hospitalized child ([Mikkelsen & Frederiksen, 2011](#); [Smith, 2018](#); [O'Connor et al., 2019](#)). It should be noted that it is a child's fundamental rights to have their parents with them at all times, also in the hospital ([European association for children in hospital, 2016](#)). The second item, which describes nurse's support

for intra-family communication, is related to the main tenet of FCC that all family members are recipients of care (O'Connor et al., 2019; Shields et al., 2006; Shields et al., 2012). This item also expressed individualized and flexible care, which is a key characteristic of FCC (Smith, 2018). The new item related to supporting intra-family communication was not subjected to evaluation by an expert panel. The researchers acknowledge that it would have been appropriate to test the comprehensibility of the sentences describing the objective of the study and the items that were modified following cognitive debriefing II.

Part of the items remained completely unchanged when the linguistic characteristics and cultural context of the original and developed scales were compared. These items were mostly within the collaboration subscale which indicates cross-cultural similarities in information sharing and the strengthening of parental involvement. The observed linguistic differences were mainly related to minor clarifications in the Finnish version. The items that were deleted from, and added to, the original scale may indicate cultural differences. The current Finnish version clearly includes issues which have been highlighted as important aspects of Finnish pediatric nursing culture in recent years (Toivonen et al., 2020).

The application of certain FCC measures on an international level have produced satisfactory results, and identified which individual factors of FCC need to be developed or improved (Aftyka et al., 2017; Seliner et al., 2016). This Finnish version of FCCAS will help to strengthen pediatric nurses' understanding of FCC because the scale includes items which comprehensively cover FCC characteristics. In this case, the FCC is more likely to be used in a clinical setting and based on the results from the viewpoints of parents, it is possible to develop the nursing towards more FCC philosophy. This developed scale will also help parents to evaluate how FCC is implemented in their child's care. The significance of multi-professional teams to FCC noticed from the expert groups should be studied further; the presented scale can be modified and targeted to each research subject.

Limitations

The FCCAS has only been validated in Turkey, but clearly corresponds to the FCC philosophy that is part of the Finnish pediatric nursing culture. Limits regarding the translation were mainly related to how the chosen translators were unfamiliar with pediatric nursing. This may explain the differences between the original and back-translated versions. The research included clinical expertise to increase the validity of the translations, but this expertise could be applied in the reconciliation phase. However, the developers of the original scale accepted the back translation without modifications. The research was also limited by the interview, as it is possible that participants not diverse enough in terms of sociodemographic characteristics which could have introduced sampling bias into the research.

Following the carefully planned interview guide promoted quality data collection and there were differences in the sociodemographic characteristics as they represented children of different ages and who had been admitted to various pediatric units. In addition, it could be expected that more concrete suggestions for development could have been formed if the cognitive interviews had been conducted in a focus group setting (Schoua-Glusberg, & Villar, 2014) which was not feasible in this study.

Conclusion

The presented results provide strong evidence that the Finnish version of FCCAS is easy to use and clear. The scale can provide many benefits to the development of pediatric nursing. Further research is needed to prove that the FCCAS is applicable to the Finnish pediatric nursing context. The systematic translation and cultural adaptation presented in this paper lay the foundation for the psychometric testing. This study chronicles the systematic translation and cultural adaptation which can also be utilized in international research. Research is relevant because a scale that is valid for the Finnish context will enable health care professionals to evaluate and track progress in the implementation of FCC. These results can then contribute to a unit's procedures, management targets and the promotion of FCC among the general public.

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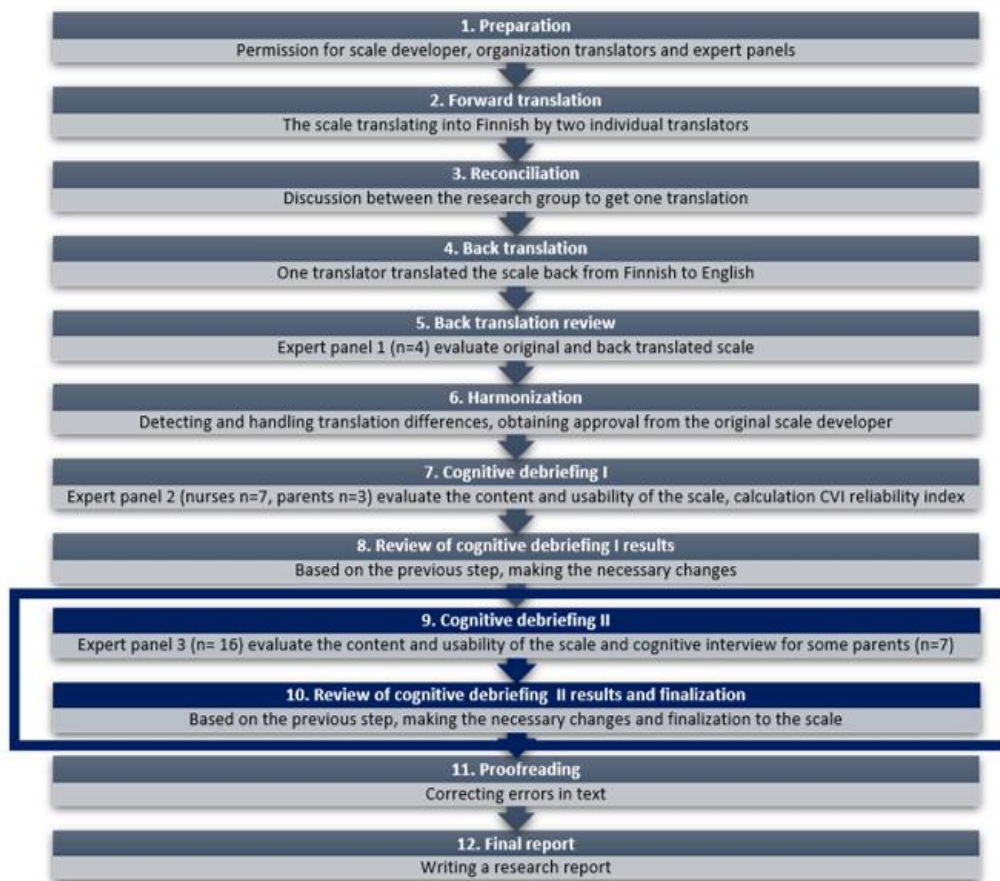


Figure 1. Phases of the translation and cultural adaptation of FCCAS. Ten phases according to ISPOR (Wild et al., 2005) and two added phases (highlighted).

Table 1. The Item-level Content Validity Index (I-CVI) values from the assessment by expert panel 2

Item (original FCCAS)	I-CVI value of FCCAS
1, 2, 3, 4, 7, 10, 11, 12, 13, 14, 16, 17, 18, 20, 21	1.00
6, 8, 9, 15, 19	0.90
5	0.40

Table 2. Examples of modifications made to items following the review of cognitive debriefing II results

The item before cognitive debriefing II	Analysis of the cognitive debriefing II results	Reasons for changing (or retaining) the item following the review of cognitive debriefing II results	The item after cognitive debriefing II results and finalization
<p>Hoitaja tukee osallistumistani lapsen hoitoon vuorokauden kaikkina aikoina (esim. mahdollisuus yöpyä lapseni luona sairaalassa)</p> <p>(The nurse supports my participation in the child's care at all times of the day (e.g. the opportunity to overnight stay with my child in the hospital))</p>	<p>Almost all thought processes were related to overnight stays</p> <p>Long item compared to others</p> <p>16/16 (100%) of the evaluations considered the item comprehensible</p> <p>5/6 (83%) of the evaluations considered the item necessary</p>	<p>The example in parentheses is unnecessary and may cause the respondent to not consider the item in a broad sense</p>	<p>Hoitaja tukee osallistumistani lapsen hoitoon vuorokauden kaikkina aikoina</p> <p>(The nurse supports my participation in the child's care at all times of the day)</p>
<p>Hoitaja saa minut tuntemaan, että hoidan lastani hyvin</p> <p>(The nurse makes me feel like I'm taking good care of my child)</p>	<p>There is some room for open interpretation in the item</p> <p>The thought processes were related to positive feedback and encouragement, which is relevant to the item</p> <p>14/16 (88%) of the evaluations considered the item comprehensible</p> <p>5/6 (83%) evaluations considered the item necessary</p>	<p>No need for changes because the content of the item may change with modification. Most of the respondents found the item understandable</p>	<p>Hoitaja saa minut tuntemaan, että hoidan lastani hyvin</p> <p>(The nurse makes me feel like I'm taking good care of my child)</p>
<p>Hoitaja kuuntelee ja huomioi lastani hänen ikä- ja kehitystasonsa huomioon ottaen</p> <p>(The nurse listens and pays attention to my child, taking into account his or her age and level of development)</p>	<p>The thought processes revealed irrelevant concepts, like listening to heart sounds or considering age in relation to nutrition</p> <p>Challenging to answer for parents with newborns</p> <p>14/16 (88%) of the evaluations considered the item comprehensible</p> <p>4/6 (67%) of the evaluations considered the item necessary</p>	<p>The words causing misunderstanding ("listen" and "age and level of development") were removed from the statement</p> <p>Changes to make it possible for parents of newborns to respond as well</p>	<p>Hoitaja huomioi lapseni yksilölliset tarpeet</p> <p>(The nurse takes into account my child's individual needs)</p>