

The content validation of the Dutch Family
Empowerment Scale,
for parents of children with a chronic condition

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Abstract

Background: Insight into parent empowerment is important to understand the impact of healthcare policy to support and strengthen parents in the care for their child. The Family Empowerment Scale (FES) is a valid measurement instrument which measures parent empowerment, originally developed for parents of children with emotional disabilities. It has been translated from English into Dutch. After translation and before using the FES in another context, the next step would be assessing content validity.

Aim: The aim of this study is to assess the content validity of the Dutch FES in the context of children with a chronic condition in a children's hospital, according to their parents and nurses.

Method: This content validity study has a convergent, mixed methods design. The quantitative part rated the relevance of items by a Dutch FES questionnaire. The content validity index was calculated.

The qualitative part assessed the comprehensiveness and comprehension of the questionnaire through cognitive interviewing. For each item, interpretations, problems and comments were analyzed.

Results: The Scale-Content Validity Index was 0.88, 10 items were advised to modify. Revisions in the first part of the questionnaire were advised in four items about clarity of wording, in the second part about tone of wording and perspective on participation for six items.

Conclusion: The content validity of the Dutch FES for parents of children with a chronic condition can be considered as sufficient. All items were considered as relevant for the concept empowerment but modifying of items is advised.

Recommendations: An introduction in the questionnaire with explanation of the concept empowerment and purpose of the questionnaire is recommended. More research is needed about the use of the FES in healthcare services and needs of parents to increase their empowerment.

Keywords: Parent empowerment, children with chronic conditions, Dutch Family Empowerment Scale, content validity

Nederlandse samenvatting

Achtergrond: Om inzicht te krijgen in de impact van interventies die gericht zijn op het versterken van ouders in de zorg voor hun chronisch zieke kind, is het belangrijk om de mate van empowerment inzichtelijk te maken. De Family Empowerment Scale (FES), is hiervoor een geschikt instrument. Het instrument is ontwikkeld voor ouders van kinderen met emotionele beperkingen en vertaald van het Engels in het Nederlands. Na vertaling en voor gebruik in een andere context is het bepalen van de content validiteit een eerste stap.

Doel: Het doel van dit onderzoek is het beoordelen van de content validiteit in de context van ouders van kinderen met een chronische ziekte in een kinderziekenhuis, door hun ouders en verpleegkundigen.

Methode: Dit onderzoek had een mixed methods design. Het kwantitatieve deel beoordeelde de relevantie van de items door middel van een Nederlandse FES vragenlijst. De content validiteitsindex werd bepaald.

Het kwalitatieve deel onderzocht de volledigheid en begrijpelijkheid van de vragenlijst door cognitive interviewing. De interpretaties, commentaren en problemen van items werden geanalyseerd.

Resultaten: The S-CVI was 0.88, voor 10 items werd aanpassing geadviseerd. Vier items in het eerste deel van de vragenlijst moeten aangepast worden op bewoording, en 6 items in het tweede deel op de toon van items en visie op participatie.

Conclusie: De content validiteit van de Nederlandse FES voor ouders van kinderen met een chronische ziekte is voldoende. Alle items zijn relevant voor het concept empowerment, maar aanpassing van items wordt geadviseerd.

Aanbevelingen: Een introductie in de vragenlijst met uitleg over empowerment en doel van de vragenlijst is belangrijk. Meer onderzoek is nodig naar het gebruik van de FES in de gezondheidszorg en de behoeften van ouders om empowerment te bevorderen.

Trefwoorden: Ouder empowerment, kinderen met een chronische ziekte, Nederlandse Family Empowerment Scale, content validiteit

In the last decennia, there has been growing attention for empowerment of a patients' family, especially for parents of a child with a chronic condition, as they are the primary caregivers of their child(1-3).

Through scientific advancement and technologies, there is now an increasing number of children living with a chronic condition(4,5). Little is known about the prevalence of chronic illness in children, partly due to the use of different definitions(6,7). In 2008, at least 14% of the Dutch children had a chronic condition(8). Mokkink et al defined four criteria when a disease or condition is considered to be a chronic in childhood: if it occurs in children aged 0 up to 18 years; the diagnosis is based on scientific medical knowledge and can be established using reproducible and valid methods and instruments according to professionals; is not (yet) curable or, for mental health conditions, is highly resistant to treatment and has been present for longer than three months, or has a high probability of lasting longer than three months, or has occurred three times or more during the past year with a high likelihood of recurrence(6).

Parents of a child with a chronic condition often provide complex care and treatment and manage their child's conditions(2,4,9,10). They may struggle since the experience can be worrisome(1,11,12). It is important for parents to be able to face this experience and to be empowered to participate in decisions and supervision of the care of their child(4,5,13-15). Empowerment is considered an important concept in strengthening parents' position in healthcare(16,17). It is described in different ways but can be defined as power that gives the ability to influence people, organizations and environments, and also gives control over one's life(13,18,19). Increased parental empowerment has a positive impact on wellbeing, self-efficacy and levels of stress and is associated with improved ability of parents to make adequate choices, such as their children's treatment(13,19).

Insight into the extent of parental empowerment is important for several reasons(20). It provides the opportunity to understand whether implemented care interventions effectively contribute to support and strengthening of parents. It also give insight in the personal degree of parental empowerment, to provide customized care that allows parents to develop empowerment.

In 1992, Koren et al developed the Family Empowerment Scale (FES) in the United States of America, a brief, self-administered, 34 item measurement scale. It gives a view of parents' own sense of empowerment at one point in time. The original version of the FES was developed for parents whose children had emotional disabilities(19). It consists of three domains: family, service system, and involvement in communities, and refers to three expressions of empowerment: attitudes, knowledge and behaviours(19,21). The FES has been translated into Dutch, amongst other languages(22). The translation from English into Dutch included a forward and backward translation, followed by a comparison with the

original English version. The Dutch translators and the authors of the FES concluded an adequate content of the questionnaire. With consent of the developers it was decided not to translate the third domain, Involvement in the community, because the content of these items was felt to be too culturally specific and not applicable to the Dutch system. Hence, the Dutch FES contains a 24 item rating scale. Today the Dutch FES is only used by Ketelaar and Hadders-Algra (2015) in a study with families of children with cerebral palsy(23).

Although the FES is a valid and reliable instrument, using in another cultural environment and with a different population than the one it was originally developed, for requires re-examination of its psychometric characteristics(21,24,25). One of the first steps is to assess the content validity. If this is adequate, evaluation of other measurement properties is useful(26). Content validity is defined as the degree to which the content of a questionnaire is an adequate reflection of the construct to be measured and should be assessed by experts, making a judgement about the relevance and the comprehensiveness of the items(27,28).

Hence, this study is a first step in contributing to a validated measurement instrument that gives insight in parental empowerment.

Aim

The aim of this study is to assess the content validity of the Dutch FES in the context of children with a chronic condition in a children's hospital, according to their parents and nurses.

Methods

Design

This content validity study has a convergent, mixed methods design. To provide reliable and complete outcomes, the two concepts of content validity, relevance and comprehensiveness, were examined separately in the same population. Data of both parts were collected during a similar timeframe and initially analyzed separately before being converged in a final analysis. The weight of outcomes of both parts was equal.

The quantitative part was a cross sectional, observational study, assessing the relevance of the items by a questionnaire(29,30). The qualitative part was a general qualitative study, assessing the comprehensibility of the questionnaire and comprehensiveness of the items through cognitive interviewing (CI) (31-33).

The Medical Research Ethics Committee of the University Medical Centre Utrecht declared this study not WMO mandatory. After information and explanation of the study, verbal and written consent of the participants was obtained.

For this study the evaluation items of The Mixed Framework were used, an eight item scale to assess mixed methods rigor(34).

Population and Sample

The population for both parts consisted of parents of children with a chronic condition and their nurses and nurse specialists as they are both considered experts in family empowerment(27). The study was conducted in an academic children hospital in the Netherlands and took six months, from January 2017 till June 2017.

The following criteria were used to include participants: parents of a child with a chronic condition as defined by Mokkink et al.(6). Nurses and nurse specialists, experienced in care of children with a chronic condition as defined by Mokkink et al., at least one year work experience. Participants had to be able to speak, write and read Dutch.

No sample size calculation was known in literature to assess content validity. Recommended sample sizes to calculate content validity quantitatively, consist of 8-12 participants(30). To assess qualitative, 7-10 participants is sufficient, but is dependent on the complexity of the instrument or diversity of population(32,33). The population of this study could be considered as diverse, there are different chronic conditions. Therefore, the sample size was greater than advised in literature.

To provide rich data, parents of children, with different chronic diseases, and nurses with experience in different chronic illness were selected by purposeful sampling(33,35). For the quantitative part of the study, 34 parents and 12 nurses were approached. From this sample, for the qualitative part, four nurses and eight parents were selected. All participants were selected by the researcher from wards where chronic ill children were admitted included outpatient clinics.

Procedure

Eligible parents were asked to participate in this study by the clinician of the child, by a nurse or the researcher (L.S.). Nurses were asked by the researcher.

When informed consent was received, participants received the FES relevance questionnaire and demographic data list from the researcher. Parents received the materials either by mail, including a reply envelope, or in person when present at the hospital; nurses received the materials in person. When no reply was received after two weeks, participants were reminded by a telephone call.

Before starting CI with participants, two pilot interviews were held by the researcher to identify ambiguities and to gain experience with CI to increase the quality of the interviews(33). Participants for the qualitative part of the study were approached by the

researcher to make an appointment with them for an interview. The interviews were audio recorded with permission of the participants.

Outcomes

The relevance of the Dutch FES was expressed in content validity index on item-level (I-CVI) and scale-level (S-CVI). The I-CVI is the number of experts giving an item of the Dutch FES a score of either 3 or 4 on the 4-point relevance scale, divided by the total number of experts (appendix 1). Polit et al. considered items with an I-CVI ≥ 0.78 as relevant, taking into account the risk of chance agreement(30). The CVI on scale-level was calculated by averaging across I-CVI values (29). A score ≥ 0.90 is considered good, a 0.80 is considered the lower limit of acceptability for a S-CVI(30).

The comprehensiveness of the questionnaire and the comprehensibility of the items was evaluated through CI, assessing participants' understanding and interpretation of the questionnaire(31-33). Participants were encouraged to think aloud when giving their interpretation of the Dutch FES items. Subsequently, the researcher asked probe questions to establish that the item was understood correctly, to inquire about not covered aspects of the concept, as well as the complexity of the questionnaire(31-33). An interview guide was used, (appendix 2). Comprehensiveness and comprehensibility was dependent on noted problems and consistent interpretation of items and the whole questionnaire.

Analysis

Quantitative part. The relevance of the Dutch FES was expressed in the content validity index (CVI)(29,30,36). For each item, the I-CVI was calculated and for the total scale the S-CVI(29),(30),

If an item wasn't completed by all experts, the I-CVI was calculated by dividing the number of experts giving a 3 or 4 rating by the total number of experts who rated this item. IBM SPSS version 22, (Armonk, New York, USA) was used.

Qualitative part. To give insight in the comprehensiveness and comprehensibility, analysis of the interviews was carried out following the method described by Knafl et al.(35). This method takes the individual item as basis of the analysis and distinguishes between interpretations and comments or problems

Data were transcribed verbatim. Interpretations of all participants were categorized per item in a scheme, with comments made regarding the items. Followed by summarizing the interviews and identification of problems per item to facilitate comparison of the participants' interpretations(32,35). A coding scheme was developed to identify themes of

the problems. To standardize, and increase the quality of the analysis, two researchers (L.S. and I.v.E.) reviewed the first five interviews for half of the items.

The summaries of essential findings of each item were analysed by two researchers. Consensus was reached by discussing and reviewing the analysis to determine major interpretations and problems. An overview was made, with for each item an evaluation about the comprehension, missing aspects of the concept and the seeming length and complexity of the questionnaire.

Converging quantitative and qualitative parts. All outcomes of the quantitative and qualitative data were combined and considered to judge the content validity and to give recommendations about the questionnaire by two researchers (L.S, I.E)(35).

Relevant and comprehensible items were recommended to retain. Relevant items, which were incomprehensible, were recommended to modify and could be retained after modification. Irrelevant but comprehensible items were eligible for retesting on relevance. Irrelevant and incomprehensible items were recommended to be deleted based. Considering modifying or deleting items, quantitative and qualitative outcomes of individual participants were weighed. Comprehensibility of parents was considered important, because they are the users of the questionnaire.

Since the original English version of the FES had good psychometric properties before translating, a special route will be followed after this study. Two independent researchers will review and assess the analysis process. The process and recommendations will be discussed with the developers of the questionnaire to make final decisions about adjustments.

Results

Participants

For the quantitative part of the study, 34 parents were invited, 22 agreed to participate. Three parents declined because they were too busy, nine parents did not return the questionnaire despite a reminder. All twelve invited nurses participated in the study (Table 1, 2). Also all participants approached for the qualitative part, four nurses and eight parents, agreed to participate. The nurses who participated in this part were specialised in Neurology, Nephrology, Muscular diseases and Pulmonology (Table 1). Children of participating parents had different diseases (Table 2).

Quantitative part

The relevance was expressed in the CVI (Table 3). The total S-CVI score was 0.88, while a 0.90 is considered as good content validity. The total I-CVI of the individual items

ranged from 0,56-1. Items 10, 12 and 24 had a score < 0.78, and were considered as not relevant by the participants. Parents rated lower than nurses, with a S-CVI of 0.85 and 0.92 respectively. They rated the items 8, 10, 12, 13, 21 and 24 lower than 0.78. Nurses rated only item 12 lower than 0.78. Item 12 was rated low, both by parents (0.52) and nurses (0.50) (Table 3).

Qualitative part

There was no difference between interpretations of nurses and parents. Therefore, responses were combined in the table (Table 4). During analysis of the interviews, six codes for problems and comments were identified: unclear wording, tone of wording, distinction of items, perspective on participation, feasibility of items, getting reliable answers, see Table 4 for definitions.

Inconsistent interpretations were observed in the first part of the questionnaire, the items one, six, seven and nine. Items one and six were seen as items with no distinction. In item one, the term “I handle” was interpreted differently. Interpretations about item six emphasized solving the problem instead of parent’s believe, which is the crux of the item. Both nurses and parents reported difficulties understanding items seven and nine. Item seven was interpreted two ways: to have a social network or to dare ask for help.

A mother about item 7: *“Ask for help? Yes, I can. Do I do that? Well no”.*

Item nine was difficult to understand and interpreted as “when there are problems, also look at the good things”. In both items, the interpretation between parents and nurses didn’t differ.

In the second part of the questionnaire and items 10 and 12, participants noted comments like different perspective on participation and tone of wording, except items 17, 18 and 23. About items 10,14,15,16,19,20,21 and 24, all parents and two nurses noticed one or more times in one or more items that they missed the notion “mutual collaboration with

Mother about item 10: *“But **I** decide what to do and then do it”, no, it isn’t really an item about empowerment because I think it’s very stupid if you do that”*

Mother about item 15: *“Well, “I make sure” that is a little firm, something like a fist on the table, now **I’m** really chairing they understand me that they really know what **I’m** thinking”*

Mother about item 16: *“If your child is aware of the problem, I can make good decisions. However, if I’m not entirely clear, what kind of problems it is this time and what assistance could fit, I do not make a decision but I first ask for help”*

Mother about item 24: *“Yes, more about tone, I think the question is clear, but I would like to do it together with mutual trust and respect. And I do not want to claim to know everything”*

professionals or others” in decisions. The tone was sometimes even experienced as offensive and egocentric by five parents and two nurses.

Item 12 was experienced as difficult to answer, different comments were made. Both nurses and parents wondered if parents give a reliable answer on this item.

Mother about item 12: *"Yes, that's always difficult, it's always so difficult. And it's essential for empowerment to have a real image of yourself"*

Father about item 12: *"You should actually ask my son. Yes, I can't quite place this item in the empowerment context"*

Item 13 showed comments about borders of family empowerment. If a parent takes a decision that is not in welfare of the child, is there the right to decide?

Mother about item 13: *"Because I think that, you can really put the parent's interest in mind rather than the child's interest".*

Comments about the possibility to get no reliable answer on items were especially made at item 12 by both nurses and parents. Parents made more often comments about feasibility of the subject of items. For example item 18, about thresholds to make contact with a clinician and item 23, about complexity of the care system.

Participants generally experienced the questionnaire not as difficult. Everybody could mentioned several aspects of empowerment, however some never heard of the concept. Especially parents recognized all items, they often answered an item from their own situation. Participants had no important additions on the questionnaire. They considered it as an improvement in care when parents complete this questionnaire regularly followed by a conversation with the professional.

Converging both Quantitative and Quantitative parts

Quantitative and qualitative parts were merged and recommendations were made for adjustments (Table 5).

Two sorts of comments (“get a reliable answer on items” and comments about feasibility of an item) where not a reason for modification. The overall purpose of the questionnaire was to gain insight into empowerment, not a reliable answer or a high score.

Fourteen items either had a consistent interpretation or no more than one participant provided an interpretation that varied substantially from all other participants, with minimal problems noted. Sometimes, participants noted problems with an unclear word, but the interpretation was consistent. This items had almost sufficient I-CVI except items eight and 21, which parents rated at 0.77. Parents who rated these items as no relevant, commented

on item eight about getting a reliable answer and on item 21 about infeasibility. Therefore, these items were considered as relevant and comprehensible and advised to be retained.

Ten items were advised to be modified. The items one, six, seven and nine were assessed as relevant, but not easily comprehensible. After modification, these items could be retained.

Items 10,12,13, and 24 were assessed as not relevant by parents, item 12 also by nurses. However, they commented that the items were clear and recognized the items. These items were considered comprehensible as well as relevant, although item 12 and 13 had some specific comments. After modification these items could be retained.

Some of these items (10 and 24), and items 15 and 16 were interpreted correctly but received many comments about perspective on participation and/or tone and therefore recommended for modification. Adjustment will mainly consist of choosing other words, reconsidering of the English version is recommended.

The items advised to be modified could be subdivided into different expressions of empowerment: two items addressing knowledge, four addressing attitude and four for behaviour.

No items were advised to be removed from the FES.

Discussion

Based on the results of this study, the content validity of the Dutch FES for parents of children with a chronic condition is considered as sufficient. Although the scale-content validity index is 0.88 and ten items were advised to be modified, all items were considered relevant and the questionnaire is comprehensive to assess empowerment. In the first part of the questionnaire, revisions in clarity of wording is needed in four items. In the second part of the questionnaire, six items need to be rephrased to improve tone and perspective.

Other published validation studies of FES translations did not investigate content validity separately. Although in the studies items were modified, based on input of experts, it was not possible to compare the outcomes of this study with other studies(13,37-39).

Important outcomes of the interviews were comments that all parents and some nurses made about their perspective on mutual collaboration with professionals, which was not addressed by the FES. It is possible that the parents in this study have a degree of empowerment where the collaboration with the professional is still very important for them. Feldman et al. described four approaches of professionals in partnership with patients or family: directing, teaching, collaboration and supporting, as a result of variation in the direction of leadership and in the degree of interaction in a situation(40). For example, collaboration assumes leadership of families and a high degree of interaction, supporting also assumes family-leadership, but requires less interaction and a high degree of

empowerment. It is possible that the parents in this study require a collaboration approach and further growth in empowerment can result in a supporting approach. In this situation, modifying these items is unnecessary.

However, parents in this study with a long-time experience in managing their children's illness, indicated they felt empowered to make decisions in situations they were familiar with. But if new problems arose because of the fluctuating course of a chronic disease, they know that collaboration with a professional was needed. These parents sometimes preferred the supporting approach and sometimes collaboration approaches, dependent on the situation of their child. This also refers to empowerment. Hence, this can explain that empowered parents with a lot of experience made also comments about tone and the lack of mutuality in making decisions and collaboration with professionals. It is possible that little adjustments of the FES like choosing other words, and reconsideration of the English translation is enough to give the FES a less egocentric view.

The lower relevance score of some items by parents could not be explained by differences between the population of parents in the original FES and this study. Sometimes, children with a chronic condition have emotional disabilities and parents of both groups have similar tasks and roles as they are the primary caregiver of their child(10,14,41). Therefore, the need for empowerment in the same areas is the same for both groups(14,42).

The participants were possibly unfamiliar with the concept empowerment. It could influence the results of the relevance study and is a limitation of this study. Some parents and nurses indicated they had never heard about empowerment before this study. Also comments in some items whether a reliable answer would be given and outcomes of item 12, the lowest relevance score, indicate unfamiliarity. Responses ranged from not relevant to very relevant. The interviews substantiate this outcome. Hence, a low I-CVI was not to be considered as a reason to delete or substantially modify an item. Adding an introduction to the questionnaire with an explanation of the concept empowerment and the purpose of the questionnaire is recommended. More attention is needed for the importance of (parental)empowerment in healthcare and associated concepts such as participation and involvement. (Parental)empowering should occupy an important place in the curriculum of education institutes.

It was difficult to include lower educated and non-native parents for both samples. This is another limitation of the study. Therefore, further research is needed about use of the FES for these groups. However, parents of children with different chronic diseases, different gender, age, education level and duration of child's illness agreed to participate. This makes the Dutch FES generalizable for parents of children with different chronic conditions.

The use of a mixed methods design to judge content validity is a strength of this study. Converging data provides a richer and more in-depth understanding of the content of

the FES. Quantitative assessment of relevance gives the possibility to compare the outcome with other content validation studies. The qualitative part gives insight in underlying thoughts and understanding in the assessment of the Dutch FES content(43,44).

In literature, the FES is applied in research to evaluate interventions(13,23,37,42,45). But participants of this study regarded the questionnaire as an instrument that could be used to give insight in the personal degree of parental empowerment. Parents could fill in the questionnaire each year and talk with their nurse or clinician about their needs and opportunities to develop in empowerment. More research is needed about this application of the FES.

After modifying the Dutch FES, reassessing of the relevance is recommended(29,30). Afterwards, the internal consistency and construct validation are next steps in the validation process(24-26).

The content validity of the Dutch FES for parents of children with a chronic condition can be considered as sufficient. Although the S-CVI is 0.88 and ten items are advised to be modified, all items are considered as relevant, comprehensible after modifying and comprehensive for the concept of empowerment. An introduction in the questionnaire with explanation of empowerment and purpose of the questionnaire is recommended. More research is needed about the use of the FES in healthcare services and needs of parents to increase their empowerment. The current study demonstrates the utility of the FES for Dutch parents, and helps focus future research on the use of the FES in health care.

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Table 1. Baseline characteristics parents

Characteristics Parents	Quant. (N=22)	Qual. (N=8)
Gender, N (%)		
Female	17 (23)	6 (75)
Male	5 (77)	2 (25)
Age, mean (\pmSD)	38 (7.7)	43 (7)
Cultural background, N (%)		
Dutch	21 (96)	7 (88)
Not Dutch	1 (4)	1 (12)
Educational level, N (%)		
High school	2 (9)	-
Trade school	9 (41)	2 (25)
Bachelors' degree	7 (32)	3 (38)
Masters' degree	4 (18)	2 (25)
Child age, mean (\pmSD)	8 (6.1)	10 (7.9)
Number of other children, mean (\pmSD)	1.4 (1.2)	1.2 (1)
Child illness (%)		
Auto immune	1 (5)	-
Gastro-enterology	4 (18)	2 (25)
Neurology	4 (18)	2 (25)
Pulmonology	6 (27)	2 (25)
Diverse syndromes	7 (32)	2 (25)
Duration of child's illness, mean (\pmSD)	6 (5.1)	6.3 (5.4)

Table 2. Baseline characteristics Nurses

Characteristics Nurses	Quant. (N=12)	Qual. (N=4)
Gender, female, N(%)	12 (100)	4 (100)
Age, mean (\pmSD)	45 (12.2)	49 (11.6)
Cultural background, Dutch, N(%)	12 (100)	4 (100)
Educational level, N(%)		
Trade school	3 (25)	2 (50)
Bachelors' degree	6 (50)	1 (25)
Masters' degree	3 (25)	1 (25)
Nursing specialization, N (%)		
Nurse specialist	3 (25)	1 (25)
Specialized nurse	9 (75)	3 (75)
Working experience (years), mean (\pmSD)	15 (12.2)	24 (13.4)
Illness specialization, N(%)		
Gastro-enterology	2 (16)	-
Muscular diseases	1 (8)	1 (25)
Nephrology	1 (8)	1 (25)
Neurology	1 (8)	1 (25)
Pulmonology	7 (58)	1 (25)

Table 3. Content validity index (I-CVI nurse, I-CVI parent, I-CVI total, S-CVI)

Item	Expres sion*	I-CVI parent	I-CVI nurse	I-CVI total
1. When problems arise with my child I handle them pretty well	Behaviors	0.96	0.83	0.91
2. I feel confident in my ability to help my child grow and develop	Attitude	0.91	0.92	0.91
3. I know what to do when problems arise with my child	Knowledge	1	1	1
4. I feel my family life is under control	Attitude	0.86*	0.92	0.98
5. I am able to get information to help me better understand my child	Knowledge	0.86	1	0.91
6. I believe I can solve problems with my child when they happen	Attitude	0.91	0.83	0.88
7. When I need help with problems in my family I am able to ask for help from others	Knowledge	0.86	0.92	0.88
8. I make efforts to learn new ways to help my child grow and develop	Behaviors	0.77*	0.83	0.78***
9. When dealing with my child, I focus on the good things as well as the problems	Behaviors	0.81	0.92	0.85
10. When faced with a problem involving my child, I decide what to do and then do it	Behaviors	0.68	0.83	0.74
11. I have a good understanding of my child's disorder	Knowledge	0.90	1	0.94
12. I feel I am a good parent	Attitude	0.52*	0.5	0.56
13. I feel that I have a right to approve all services my child receives	Attitude	0.72	0.91	0.79
14. I know the steps to take when I am concerned my child is receiving poor services	Knowledge	0.95**	1	0.97
15. I make sure that professionals understand my opinions about what services my child needs.	Behaviors	0.81*	1	0.88
16. I am able to make good decisions about what services my child needs	Knowledge	0.96	1	0.97
17. I am able to work with agencies and professionals to decide what services my child needs	Knowledge	0.96	1	0.97
18. I make sure I stay in regular contact with professionals who are providing services to my child.	Behaviors	1	1	1
19. My opinion is just as important as professional's opinions in deciding what services my child needs	Attitude	0.82	0.92	0.85
20. I tell professionals what I think about services being provided to my child	Behaviors	0.89	0.98	0.85
21. I know what services my child needs	Knowledge	0.77	1	0.85
22. When necessary, I take the initiative in looking for services for my child and my family	Behaviors	1	1	1
23. I have a good understanding of the service system that my child is involved in	Knowledge	0.89	0.96	0.85
24. Professionals should ask me what services I want for my child	Attitude	0.68	0.92	0.77
S-CVI, $\geq 0,9$ is good content validity		0.85	0.92	0.88

* 1 missing data

** 2 missing data

*** By recalculation in connection with missing data is item now relevant, first: P I-CVI: 0.72 , Total I-CVI 0.765

Table 4. Outcomes cognitive interviews

Types of problems and definition:	
<p>Unclear wording: comments on a word or sentence that can be understood in several ways, multiple meanings Tone of wording: comments about wording that is confusing, offensive. Or makes the overall tone of the item overly negative. Feasibility: comments about wondering if it is feasible what the item poses, participants understand the item Perspective: participants have another perspective on the subject of the item Distinction of items: comments about items resemble each other Reliable answer: comments about the possibility parents may not give a reliable answer to the item or the item is experienced as subjective</p>	
1. When problems arise with my child, I handle them pretty well.	
<i>Interpretations:</i> Parents can handle, deal with, take action, estimate, decide, resolve, problems seen in context of parent/child	<i>Problemtype:</i> Unclear wording: Uncertainty about “problems” and “pretty well”; sufficient unambiguously interpretation of this words
2. I feel confident in my ability to help my child grow and develop.	
<i>Interpretations:</i> The parent feels in balance / sure in upbringing of child, despite illness of the child	<i>Problemtype:</i> 2 parents: Item could be confronting; 1x unclear wording: “ability”
3. I know what to do when problems arise with my child.	
<i>Interpretations:</i> Solving problems by doing/undertaking, action. Problems are interpreted in the context of parent and child	<i>Problemtype :</i> 3 nurses: unclear wording: “which problem”, interpretation is clear; 1x: item looks like item 1
4. I feel my family life is under control.	
<i>Interpretations</i> The family is in balance, there is a passable rest	<i>Problemtype:</i> 2 nurses, 1 parent: unclear wording: what is control, but clear interpretation
5. I am able to get information to help me better understand my child.	
<i>Interpretations:</i> Parent has the ability to look for information about the disease / consequences or development.	<i>Problemtype:</i> Different once-only problems: Solid tone, reliability answer, unclear word: information
6. I believe I can solve problems with my child when they happen.	
<i>Interpretations:</i> The parent can solve a problem by doing something.	<i>Problemtype:</i> 1 nurse, 3 parents: feasibility: many (medical) problems cannot be solved; 1 nurse, 2 parents: distinction between items 1,3,5; 1 nurse, 3 parents: unclear wording: 3x “problems: is a broad concept; 1x difference solve and do
7. When I need help with problems in my family, I am able to ask for help from others.	
<i>Interpretations:</i> The parent has the opportunity to ask for help (network, professional) and also dare to ask for help	<i>Problemtype:</i> 2 nurses, 3 parents: unclear sentence: two opportunities: to have a network and to dare; 1x unclear wording: who are “others”; 1x tone: problems is negative
8. I make efforts to learn new ways to help my child grow and develop.	
<i>Interpretations:</i> The parent wants to learn new ways that match the child's development. 1 parent: understanding the child in the disease process	<i>Problemtype:</i> 2x nurses: give parent reliable answer; parents: 1x unclear wording: “make efforts”; 1x unclear sentence; 1x tone of item is offensive
9. When dealing with my child, I focus on the good things as well as the problems.	

<i>Interpretations:</i> In case of problems it is important to look also at what is going well.	<i>Problemtype:</i> 1 nurse and 2 parents: unclear sentence about focus of question and “as well as”. 1x worrying tone, 1x it’s going often about problems
10. When faced with a problem involving my child, I decide what to do and then do it.	
<i>Interpretations:</i> In case of problems, the parent decides, but in medical situations, the professional also decides. Problems are interpreted as medically.	<i>Problemtype:</i> 1 nurse, 5 parents: perspective: parents often don’t decide only, feelings of dependence on professional in a decision; 2 parents: older children engage in decisions; 1 nurse, 1 parent: tone of wording: 2x demanding
11. I have a good understanding of my child’s disorder.	
<i>Interpretations:</i> Parents understand the child’s illness (but not always the consequences / expressions)	<i>Problemtype:</i> 3x parents: feasibility: The effects of the disorder are not always understandable
12. I feel I am a good parent.	
<i>Interpretations:</i> The parent has the confidence doing it well enough, but it is difficult to say for yourself	<i>Problemtype:</i> 2 nurses, 2 parents: feasibility, is it possible to do it right, what is good enough? 2 nurses, 2 parents: reliable answer by parents, difficult to say it for yourself
13. I feel that I have a right to approve all services my child receives.	
<i>Interpretations:</i> The parent has the right to say the choice of treatment of their child	<i>Problemtype:</i> 2 nurses, 2 parents: vision: welfare of child is a border of the parents’ right to approve; 2 parents: feasibility, parents feel depend on physician
14. I know the steps to take when I am concerned my child is receiving poor services.	
<i>Interpretations:</i> The parent is not satisfied with the care, it may be better, the care is not good, not the right care	<i>Problemtype:</i> 3x unclear wording: 1 parent: “concerned” is vague, 2 nurses: what is “poor services”; 2 nurses, 1 parent: tone/perspective: business tone, conversation is better.
15. I make sure that professionals understand my opinions about what services my child needs.	
<i>Interpretations:</i> The parent tells his / her opinion to the professional (clinician) who understands it.	<i>Problemtype:</i> 2x unclear wording: unclear sentence; 1 nurse, 2 parents: other perspective on participation; 1 nurse, 3 parents: tone of item is offensive
16. I am able to make good decisions about what services my child needs.	
<i>Interpretations:</i> The parent makes choices about the care of their child, but after advice and in consultation with professional (clinician)	<i>Problemtype:</i> 1 parent: reliable decision parents; 2 nurses, 7 parents: perspective: dependency of parent on the professional, emphasize deciding in collaboration
17. I am able to work with agencies and professionals to decide what services my child needs.	
<i>Interpretations:</i> The parent can work with different professionals for good care for the child	<i>Problemtype:</i> 1x tone/perspective (collaboration important), 1x unclear wording (clear for foreigners?), parents: feasible for various reasons
18. I make sure I stay in regular contact with professionals who are providing services to my child.	
<i>Interpretations:</i> The parent considers contact with the professional important and takes the initiative	<i>Problemtype:</i> Feasibility: 1 nurse: worried about to much contact 3 parents: experienced high threshold in possibility to contact
19. My opinion is just as important as professionals’ opinions in deciding what services my child needs.	
<i>Interpretations:</i>	<i>Problemtype:</i>

Parent's opinion is just as important as the opinion of the professional	5 parents: perspective: different perspectives: 1 parent: parents opinion is more important, 1 parent: equal weight of opinion, 3 parents: opinion of professional sometimes more important
20. I tell professionals what I think about services being provided to my child.	
<i>Interpretations:</i> The parent gives feedback to the professional about the care for the child	<i>Problemtype:</i> 2 nurses, 2 parents: tone of wording offensive; 1x feasibility; 1x perspective on collaboration; 1x unclear wording ("services")
21. I know what services my child needs.	
<i>Interpretations:</i> The parent knows what care is needed by knowledge and experience	<i>Problemtype:</i> 1x distinction of items; 1x unclear word (which care); 1 parent: reliable; 4 parents: perspective: professional is required to know what is possible
22. When necessary, I take the initiative in looking for services for my child and family.	
<i>Interpretations:</i> The parent is looking for care, family is not always mentioned	<i>Problemtype:</i> 1x focus unclear: child or family; 1x feasibility; 1x services instead of care; 1x perspective: empowerment means together
23. I have a good understanding of the service system that my child is involved in.	
<i>Interpretations:</i> The parent understands the care system: all healthcare providers and the whole care system (wide)	<i>Problemtype:</i> 4 nurses, 5 parents: feasible, care system is complicated; 1x unclear wording (care system, broad)
24. Professionals should ask me what services I want for my child.	
<i>Interpretations:</i> The professional should ask the parent what he/she wants.	<i>Problemtype:</i> 3 nurses, 3 parents: toon of wording is aggressive; 6 parents: perspective about collaboration with professional, mutual is important.
Introduction	
<i>Interpretation:</i> Several interpretations: independent reply of items, how do parents deal with the illness of their child, does the parent have an opinion in the child's care?	<i>Problems:</i> 1x unclear sentence: "We realize that other people may be involved in the care of decisions about your child" <i>Conclusion:</i> In introduction explanation about purpose of questionnaire and empowerment
Concept empowerment	
<i>Interpretations:</i> Having power, dealing with problems / illnesses, standing up for yourself, managing yourself and problems, organizing everything for your child, can also ask for help in time	<i>Problemtype:</i> 1x: no Dutch translation for empowerment; 1 nurse, 2x parents: never heard of the word empowerment before this study <i>Conclusion:</i> Several aspects of empowerment are mentioned, some unambiguousness: "self", "can"
Difficulty of questionnaire	
<i>Difficulty:</i> 2 parents, 2 nurses: difficult 6 parents, 2 nurses: not difficult	<i>Problems:</i> 1x items with no distinction, 1x empowerment isn't explained, 2x difficult for foreigners? 3 parents, 2 nurses: conversation is important <i>Conclusion:</i> Questionnaire isn't difficult for parents, conversation is important

Table 5. Advice about items

Item	Advice
1. When problems arise with my child I handle them pretty well	Modify: "Handle" has several interpretations, therefore no distinction with item 3.
2. I feel confident in my ability to help my child grow and develop	Retain: unambiguous interpretation, minimal problems
3. I know what to do when problems arise with my child	Retain: unambiguous interpretation, minimal problems
4. I feel my family life is under control	Retain: but attention for the word control, can be unclear for degree of control
5. I am able to get information to help me better understand my child	Retain: clear interpretation, sometimes dependent of the context, is no problem
6. I believe I can solve problems with my child when they happen	Modify: interpretations about solving the problem, not about believe of the parent "I believe I can", which is the crux of the item. "Problems" is unclear, but unambiguous interpretations, depend of context.
7. When I need help with problems in my family I am able to ask for help from others	Modify: unambiguous interpretation, but understanding in two ways.
8. I make efforts to learn new ways to help my child grow and develop	Retain: minimal difference in interpretation. Reliability problems solving by explanation in introduction about empowerment (it is not about right or wrong)
9. When dealing with my child, I focus on the good things as well as the problems	Modify: clear interpretations, but starting point looks like problems.
10. When faced with a problem involving my child, I decide what to do and then do it	Modify: unambiguous interpretations, but problems: deciding is in consultation with professional, children engage in decisions
11. I have a good understanding of my child's disorder	Retain: but consider if another word for disorder is needed.
12. I feel I am a good parent	Modify: unambiguous interpretations, but difficult to say it for yourself. Problems: reliability, feasibility
13. I feel that I have a right to approve all services my child receives	Modify: as far as it is in the interests of the child. Parents don't always have the right (welfare of child)
14. I know the steps to take when I am concerned my child is receiving poor services	Retain: problems with unclear wording, but unambiguous interpretation. Tone of item: is rigor, but doesn't exclude conversation
15. I make sure that professionals understand my opinions about what services my child needs.	Modify: tone of item is offensive. Unambiguous interpretation
16. I am able to make good decisions about what services my child needs	Modify: collaboration with professional
17. I am able to work with agencies and professionals to decide what services my child needs	Retain: unambiguous interpretation, several minimal problems.
18. I make sure I stay in regular contact with professionals who are providing services to my child.	Retain: unambiguous interpretation, problems no reason to modify item
19. My opinion is just as important as professional's opinions in deciding what services my child needs	Retain: unambiguous interpretation, different visions on weight of opinion. Conversation about questionnaire is important.
20. I tell professionals what I think about services being provided to my child	Retain: unambiguous interpretation, tone is offensive, maybe modifying other items on tone can change the experience of tone of the entire questionnaire
21. I know what services my child needs	Modify: unambiguous interpretation, problems with vision: collaboration with professional
22. When necessary, I take the initiative in looking for services for my child and my family	Retain: unambiguous interpretation, focus on family not always clear, but retain
23. I have a good understanding of the service system that my child is involved in	Retain: unambiguous interpretation, parents experienced difficulties in understanding the care system. Conversation about item is important.
24. Professionals should ask me what services I want for my child	Modify: unambiguous interpretation, problems with tone and perspective on collaboration with professional (together)

Appendices

Appendix 1

Family Empowerment Scale

Empowerment is een begrip dat steeds vaker tegenkomen in de gezondheidszorg. Family Empowerment betekent "Het versterken van het gezin om zelf beslissingen te nemen de omgeving (mensen en organisaties en controle te krijgen over het leven (en gezin). De stellingen in deze vragenlijst zijn ontwikkeld om "empowerment" van ouders te meten. Het eerste deel van de vragenlijst bevat stellingen die gaan over empowerment van ouders in het omgaan met hun kind en gezin, het tweede deel gaat over de empowerment van ouders in relatie tot de zorgverlening aan hun kind.

Lees ieder item goed door en vraag u af of deze stellingen u relevant is in een vragenlijst waarmee we empowerment van ouders met een chronisch ziek kind/ kind opgenomen op de NICU willen meten. Betrek daar bij ieder deel van de vragenlijst het onderwerp (gezin of zorgverlening) en kijk ook of het past bij de betekenis van empowerment. Het is fijn als u aanvullingen, commentaar of andere opmerkingen wilt noteren in het vakje opmerkingen onderaan deze vragenlijst.

	<u>Over uw gezin</u>	<i>hoeft niet ingevuld te worden</i>				Helemaal niet relevant	Een beetje relevant	Relevant	Heel erg relevant
		nooit	zelden	soms	vaak				
<u>1</u>	Wanneer er zich problemen voordoen met mijn kind, kan ik die redelijk goed hanteren	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>2</u>	Ik voel mij zeker in mijn vermogen om mijn kind te helpen opgroeien en ontwikkelen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>3</u>	Ik weet wat ik moet doen wanneer er zich problemen voordoen met mijn kind	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>4</u>	Ik heb het gevoel dat mijn gezinsleven onder controle is	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>5</u>	Ik weet hoe ik informatie moet krijgen die me helpt mijn kind beter te begrijpen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>6</u>	Ik denk dat ik de problemen met mijn kind kan oplossen wanneer die zich voordoen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>7</u>	Ik kan hulp aan derden vragen wanneer ik hulp nodig heb bij problemen met mijn gezin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>8</u>	Ik doe mijn best om nieuwe manieren te leren om mijn kind te helpen opgroeien en ontwikkelen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>9</u>	Bij het omgaan met mijn kind let ik zowel op de dingen die goed gaan als op de problemen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>10</u>	Wanneer ik geconfronteerd wordt met problemen met mijn kind beslis ik wat er gedaan moet worden en doe ik dat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>11</u>	Ik begrijp de aandoening van mijn kind goed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>12</u>	Ik vind dat ik een goede ouder ben	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

	<u>Over de zorgverlening aan uw kind</u>	nooit	zelden	soms	vaak	Helemaal niet relevant	Een beetje relevant	Relevant	Heel erg relevant
13	Ik vind dat ik het recht heb om al of niet akkoord te gaan met de zorg die mijn kind krijgt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
14	Ik weet welke stappen ik moet ondernemen als ik vermoed dat mijn kind slechte zorg krijgt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
15	Ik zorg ervoor dat professionals begrijpen welke mening ik heb over de zorg die mijn kind nodig heeft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
16	Ik kan goede beslissingen nemen over de zorg die mijn kind nodig heeft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
17	Ik ben in staat om samen te werken met instanties en professionals om te besluiten welke zorg mijn kind nodig heeft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
18	Ik zorg ervoor dat ik regelmatig contact heb met die professionals die zorg aan mijn kind verlenen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
19	Mijn mening is net zo belangrijk als de mening van de professionals bij de besluitvorming over welke zorg mijn kind nodig heeft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
20	Ik vertel professionals wat ik vind over de zorg die verleend wordt aan mijn kind	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
21	Ik weet welke zorg mijn kind nodig heeft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
22	Indien nodig neem ik het initiatief om zorgverlening voor mijn kind en mijn gezin te zoeken	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
23	Ik begrijp het zorgstelsel rondom mijn kind goed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
24	Professionals zouden mij moeten vragen welke zorg ik wil voor mijn kind	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

Aanvullende opmerkingen

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Appendix 2

Type cognitive probe	Probe vragen
Begrijpelijkheid en interpretatie	<ul style="list-style-type: none">• Kunt u me in eigen woorden vertellen wat de introductie betekent?• Wat betekent de term empowerment voor u?• Wat denkt u bij deze vraag?
Duidelijkheid van de items	<ul style="list-style-type: none">• Kunt u de vraag in uw eigen woorden herhalen?
Specifiek Algemeen	<ul style="list-style-type: none">• Waarom zegt u dat het belangrijk is?• Hoe komt u op dat antwoord?• Zou u ooit antwoord 1 kiezen? Waarom wel of waarom niet? In welke situatie zou u antwoord 4 kiezen?• Was het makkelijk of moeilijk te beantwoorden?• Ik zag dat u aarzelde, kunt u me vertellen wat u dacht?• Kunt u me daar meer over vertellen?• Zijn er woorden of omschrijvingen die u zou willen veranderen?
Vragen omtrent de vragenlijst in zijn algemeen	<ul style="list-style-type: none">• Welke andere ervaringen heeft u met empowerment die niet gevraagd worden in deze vragenlijst?• Zijn er ook andere punten waar u aan denkt bij empowerment en niet worden genoemd in deze vragenlijst?
Vragen omtrent vragenlijst om te bepalen of de participant moeite heeft met de presentatie van de vragenlijst.	<ul style="list-style-type: none">• (<i>Observatie van manier waarop de participant de vragenlijst invult. Noteer gezichtsuitdrukkingen indicatie voor moeilijkheden met lezen, heen en weer kijken op de vragenlijst. Luister naar opmerkingen over moeite met het lezen van de vragen indicatie over gebrek aan duidelijkheid of gebruiksgemak.</i>)• Welke suggesties heeft u om de vragenlijst te veranderen om deze makkelijker in te kunnen vullen?
Tijdsduur	<ul style="list-style-type: none">• Wat vindt u van de tijd die u nodig heeft om de vragenlijst te beantwoorden?