

# **Evaluating content validity of the Dutch translation of the Family Empowerment Scale in the Neonatal Intensive Care Unit using mixed methods**

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## **Abstract**

**Title** Evaluating content validity of the Dutch translation of the Family Empowerment Scale in the Neonatal Intensive Care Unit using mixed methods.

## **Background**

Parents of infants, admitted to a Neonatal Intensive Care Unit (NICU), experience stress and feelings of helplessness. Involving parents in daily care helps them taking their parental role. This process of informing parents, learning to care and involvement in decision making is described as family empowerment. The Dutch translation of the Family Empowerment Scale (FES), might be an instrument to measure parents ability to gain knowledge, skills, their participation in care and shared decision making.

## **Aim**

Evaluating content validity of the Dutch translation of the FES, in terms of relevance and comprehensiveness, in the NICU.

## **Method**

This observational convergent mixed methods study quantitatively assessed relevance of items, using the Content Validity Index (CVI). Comprehensiveness was studied qualitatively using cognitive interviews. Results of both analyses were converged to determine content validity of the FES.

## **Results**

Relevance of items scored .73 in total by CVI . Interviews showed problems with participants understanding the introduction, and their familiarity with the concept of empowerment. Furthermore, where problems and services were included in the items these were interpreted as medical. However when items were related to daily care, participants expressed the importance of involvement and decision making.

## **Conclusion**

The FES showed weak content validity in terms of relevance on CVI, however interviews showed strong evidence when items would refer to daily care.

## **Recommendations**

Based on our results, it is recommended to adjust the introduction to explain the concept of empowerment and the context within which participants should judge the items. Further studying the adjusted FES, to determine content validity, could provide nurses with a validated tool to measure empowerment in NICU parents.

**Keywords** Empowerment, content validity, NICU, mixed methods, cognitive interviewing.

## **Dutch Summary**

**Titel:** Evaluatie van content validiteit van de Family Empowerment Scale, de Nederlandse vertaling, op de Neonatale Intensive Care Unit, een mixed methods studie.

### **Achtergrond**

Ouders van kinderen opgenomen op de NICU, ervaren stress en gevoelens van hulpeloosheid. Door ouders actief te betrekken bij de zorg kunnen ouders hun ouderrol oppakken. Dit proces van informeren, leren zorg te dragen en betrokkenheid bij besluitvorming wordt wel omschreven als familie empowerment. De Nederlandse vertaling van de Family Empowerment Scale (FES) kan een instrument zijn om dit vermogen van ouders, om kennis te vergaren, vaardigheden te ontwikkelen en te participeren in besluitvorming, te meten.

### **Doel**

Evaluatie van content validiteit van de Nederlandse vertaling van de FES, in termen van relevantie en begrijpelijkheid, op de NICU.

### **Methode**

Deze observationele mixed methods studie onderzocht kwantitatief relevantie van items, met behulp van Content Validity Index (CVI). Cognitieve interviews zijn gebruikt om begrijpelijkheid van items kwalitatief te onderzoeken. Resultaten zijn samengevoegd om de content validiteit te bepalen.

### **Resultaten**

Relevantie van items, CVI scoorde .73. Interviews onthulden onbekendheid met het concept empowerment en interpretatie problemen met de introductie tekst. Verder waar problemen en zorg in de items werden genoemd, werden deze vooral geïnterpreteerd als medisch. Echter wanneer items betrekking zouden hebben op dagelijkse zorg benadrukten participanten het belang van betrokkenheid en gedeelde besluitvorming,

### **Conclusie**

De FES scoorde zwak inzake relevantie. Daarentegen bewezen interviews validiteit indien items zouden verwijzen naar de dagelijkse zorg.

### **Aanbevelingen**

Gebaseerd op onze resultaten, is aanpassing van de introductie tekst aan te bevelen. Zodat het concept van empowerment en de context waarbinnen ouders de items moeten invullen, kan worden uitgelegd. Aansluitend onderzoek met deze aangepaste FES om de content validiteit te bepalen, kan NICU verpleegkundigen een gevalideerd instrument om empowerment bij ouders te meten opleveren.

**Sleutelwoorden:** Empowerment, content validiteit, NICU, mixed methods, cognitieve interviews.

Transition into parenthood and giving birth to a healthy infant is a significant change in the life of a family. Unexpected admission to the Neonatal Intensive Care Unit (NICU) is a complication with associated anxiety for parents, and is known to cause significant stress<sup>1-4</sup>. Admission to the NICU hampers the bonding process between infant and parents, which normally starts directly after birth<sup>1,5</sup>. Parent's participation in the care for their infant, the first few days after birth, might be hindered, which leads to feelings of helplessness<sup>6</sup>. Parents of infants admitted to a NICU, are relying on nurses for the best interest of their infant<sup>1</sup>.

It is important for parents to take over their parental role, in order to form a meaningful bond with their infant. Hereby developing the ability to take care for their infant at dismissal from the NICU<sup>6-8</sup>. This parental involvement in care processes and shared decision making, is also described to be beneficial for parents<sup>9,10</sup>. Nurses have the responsibility to give parents access to the services and resources they need, to enable families to increase their social power and hereby becoming more empowered<sup>5,11,12</sup>. Nurses at a NICU acknowledge this partnership by helping parents to gain confidence<sup>7,8,13</sup>. This process in which families gain knowledge, skills, and resources to enable them to gain positive control over their lives is also described as family empowerment<sup>11,14</sup>.

An instrument to measure parent empowerment, provides nurses the possibility to assess parents ability to participate in shared decision making, gain knowledge and develop skills. Helping nurses to tailor interventions towards empowering parents. The Family Empowerment Scale (FES), by Koren et al (1992), was developed to provide professionals with an instrument to measure empowerment in parents of children with emotional disabilities<sup>15</sup>. The FES measures empowerment at three levels: Family, Service system and Community/political. And the three ways in which empowerment is expressed, namely behaviours, knowledge and attitudes<sup>15</sup>. The FES is proven to be a valid and reliable instrument to get a "snapshot" overview of parental empowerment. It is used in over 50 studies, in several countries and populations<sup>16,17</sup>. It has also been translated into various languages<sup>18,19</sup>.

Ketelaar and Hadders-Algra (2015) translated the FES into Dutch, for use in a study with families of children with cerebral palsy<sup>20</sup>. They believed the content of the level Community/political, to be too culturally sensitive and not applicable to the Dutch system. Therefore, with consent of the developers, it was decided not to use or translate this level for the Dutch population. The levels Family and Service system were, after resolving discrepancies, translated into Dutch by two independent researchers. This translation was back translated into English by an English native speaker. The Dutch translators and the authors of the original FES, compared this translation with the original and concluded that the translated version was adequate.

Before using a valid and reliable instrument in another country, culture or population from which it was originally developed, its psychometric characteristics must be examined again<sup>21,22</sup>. Content validity, one of the first steps in validity research, focuses on whether the content of the instrument fits the construct that one intends to measure, with regard to relevance and comprehensiveness<sup>23</sup>. Hereby capturing the connection between the intended measurement concept and the way participants from the target population understand and discuss that concept<sup>24</sup>. Experts judge relevance of items for construct, patient population and purpose<sup>25</sup>. Comprehensiveness of items refers to understanding of the items. Comprehensiveness of content is evaluated by verifying if important items are included to cover the targeted concept<sup>26</sup>.

### **Aim**

This study aims to evaluate the content validity, in terms of relevance and comprehensiveness, of the Dutch translation of the FES in a population of parents of infants admitted to, and nurses working at, the NICU.

### **Method**

#### **Design**

This observational, convergent mixed methods study, was conducted at the Neonatal ward of the University Medical Centre Utrecht, in the Netherlands. Mixed methods was used to combine the strength of quantitative and qualitative research. Merging data after analysis, also contributed to a richer and deeper understanding of the data<sup>27-29</sup>.

Quantitative data to determine relevance of items, was collected cross sectional. Content Validity Index (CVI), is an evidence based method of quantitatively estimating content validity of a scale by relevance of items<sup>30</sup>. CVI determined if the FES had an appropriate sample of items to measure the concept of empowerment. The study version of the FES, (Appendix A), scored relevance for construct, population and purpose. Since no clear sample size calculations are available for assessing content validity, a sample of 30 participants, based on admission rate of the NICU, seemed feasible to determine content validity of the FES<sup>30,31</sup>. Parents and nurses are considered experts concerning family empowerment, therefore both were invited to participate<sup>25</sup>. A  $\pm$  2:1 ratio, parents, nurses, was chosen because parents are seen as the one with the most expertise regarding family empowerment. Furthermore parents are the target population for administering the FES. For the questionnaires, a consecutive sampling approach was used, based on eligibility and availability.

The evidence based, qualitative method of cognitive interviewing was used to assess comprehensiveness<sup>32-34</sup>. Comprehensiveness of items was determined through participants'

interpretations and understanding of the FES. A nested convenience sampling approach was used, based on availability of participants. A semi structured interview guide, developed by researchers IE and LS, (Appendix B), helped to structure the interviews. Participants were invited to read the items of the FES aloud and were encouraged to comment on relevance, comprehensiveness and clarity of items. The interviewer asked probe questions to elicit detailed information. The thinking aloud method helped to gain insight in the thought processes of participants. All interviews were audiotaped.

Data were collected concurrently, however analysis of data was performed separately. By merging the data, through comparing and contrasting the results of the two separate analyses, a more complete understanding of participants interpretations according relevance and comprehensiveness, was determined. In order to evaluate the content validity of the FES. The mixed framework by Eckhardt and Devon (2017) helped to achieve rigor in this mixed methods research<sup>35</sup>.

### **Participants and procedures**

Data collection took place from February 2017 until May 2017. In February two pilot interviews to test the interview guide and audio taping equipment, and to improve interview style were performed.

Parents of children admitted to the NICU > 48 hours, without irreversible prognosis of imminent death, were consecutively approached by the researcher, informed and invited to consider participation in this study. They were given a minimum of four days to consider participation. Mastering the Dutch language was an inclusion criterion for all participants. After signing informed consent (IC), the study version of the FES and the questionnaire to obtain demographic characteristics were handed over.

Experienced, NICU certified, nurses were informed by e-mail, and in two information sessions at the NICU. Nurses were informed about the aim of the study and invited to consider participation. After signing IC, they were handed over the study version of the FES and the demographic characteristics questionnaire.

After completion of the questionnaires, participants, both parents and nurses, were invited to participate in the interviews.

### **Data analysis**

Demographic characteristics, to describe baseline variables, were analyzed by using descriptive statistics, IBM SPSS version 22, (Armonk, New York, USA), and presented using count, mean, standard deviations, median and percentages.

### **Relevance**

The CVI data were analyzed as Item CVI (I-CVI) and Scale-CVI/Average (S-CVI/Ave). For I-CVI ratings of relevance, the FES items were judged separately on a four point scale, 1 not relevant, 2 little relevant, 3 relevant, 4 very relevant. The participants who scored  $\geq 3$

were divided by the total of participants scoring, hereby calculating the proportion in agreement about relevance. An I-CVI  $\geq .78$  with  $\geq 3$  participants is considered evidence of good content validity<sup>30</sup>. S-CVI/Ave is the average I-CVI across items, a S-CVI/Ave of .80 is considered the criterion lower limit of acceptability for a S-CVI/Ave by scale developers<sup>30,36</sup>.

If five or less percent of data was missing per item, a complete case analysis was performed. If more than five percent of data was missing no reliable I-CVI could be assessed. A corrected score, based on available cases, is reported but these items were decided beforehand to be irrelevant.

### **Comprehensiveness**

Analysis of interviews started with transcribing the interview data verbatim. The verbatim transcriptions were used to summarize interpretations and comments of participants. A report was generated per item. Types of problems were inductively derived using this descriptive summary of items. Standardization for summarization and categorization was achieved as followed. Researchers independently summarized and categorized five interviews. The summary and categorization of these interviews were compared and discussed, in order to indicate if the summaries correctly reflected participants' statements. After consensus was reached remaining data were analysed. An overview of interpretations and problems in order to evaluate comprehensiveness, and clarity of items, is shown in Table 1.

### **Converging results**

The researchers discussed all results of the I-CVI and the interviews per item, to get an overall interpretation of the data, and determine relevance and comprehensiveness. Opinions of parents were compared and weighed with nurses', in order to make consistent recommendations concerning modification of items, adjusting the introduction of the FES or ways to administrate the FES. Hereby knowledge of empowerment, the intended measurement concept, by participants was taken into account. Outcomes of both analyses, the recommendations based on converging outcomes and comments of participants during interviews, formed the base for an overall view on content validity and overall recommendations.

### **Ethical considerations**

The Medical Research Ethics Committee of the UMCU decided that according to the Medical Research involving Human Subjects act (WMO) this study was not WMO mandatory, METC-protocol number 17-035/C. This study was conducted according to the principles of ICH Good Clinical Practice (GCP), applicable subject privacy requirements, and the guiding principles of the declaration of Helsinki<sup>37,38</sup>.

## Results

### Participants

In this study 46 parents were informed, from which 23 signed informed consent. Of these 23, three parents were excluded, because their infants were transferred before the questionnaires were returned by their parents. Reasons for not participating in the study were expressed feelings of stress and anxiety due to NICU admission, early transfer to another hospital and language problems. Educational level of parents in the quantitative sample was 75% bachelor or higher, in the interviews 77,8%.

In total 103 nurses were informed of which 14 were willing to participate in the study. Finally 11 nurses were included after signing IC.

In the quantitative part of the study 20 parents and 11 nurses participated. From this sample 13 participants, nine parents (one couple), and four nurses, participated in 12 interviews. Table 2 shows all baseline characteristics of participants.

### Relevance

I-CVI's ranged from .52 to .97, seven items scored an I-CVI  $\geq$  .78, (see Table 3). Two of the seven relevant items, item 14 and 18, with a total I-CVI of respectively .87 and .97, were considered relevant by both parents and nurses. Parents rated 16 items to be relevant in this setting, ranging from .8 to 1.0, nurses rated three items to be relevant, ranging from .82 to .91. One of the two items with >5% missing data, Item 7, scored relevant based on corrected outcomes, this item was however considered irrelevant.

The S-CVI/Ave was calculated at .73 for all participants, .84 in parents and .53 in nurses.

### Comprehensiveness

Participants' interpretations, concerns on comprehensibility, comments on relevance and general remarks about the questionnaire during the interviews, were used to determine comprehensiveness.

Main findings were problems with interpretability of items, applicability, feasibility and comprehensiveness, in both parents and nurses. The introduction of the FES turned out to be multi interpretable. Three participants did not understand the aim of the questionnaire and three parents missed explanation of the concept of empowerment. Furthermore not all participants were familiar with the concept of empowerment. Two nurses described empowerment well and three parents expressed professional knowledge regarding empowerment.

All participants expressed difficulties to distinguish the two levels of empowerment in the questionnaire: Family and Service system, the two distinct parts of the questionnaire. Regarding the first 12 items: About your family, participants expressed that in the NICU normal life is on hold; 'it is all about medical decisions, there are no feelings of family life present, it feels like living in a bubble' and decisions are made by NICU professionals.

Five items were rated as comprehensive and applicable. Interpretation of these items was consistent, only minimal problems were seen with clarity, wording or tone (see Table 1). One of these items, item 7 “*When I need help with problems in my family I am able to ask for help from others*”, was interpreted differently by participants. However, difficulties in interpretation of item 7 did not seem to be problematic for most participants. After weighing the comments about importance, item 7 was therefore considered comprehensive. In item 20, “*I tell professionals what I think about services being provided to my child*”, participants expressed problems with interpretation of the answers.

*“I think little parents are really honest about this” (N12)*

Six parents emphasized the importance of this item, one parent and one nurse expressed the contribution of this item to a feeling of empowerment.

In fourteen items, problems with interpretability, clarity, wording and/or tone were expressed, (see Table 1). Eight of these items showed difficulties in interpreting problems and services. In the first part of the questionnaire: About your family, problems referred to, were interpreted as medical. Handling, acting, solving and deciding regarding these problems was thereby considered impossible for parents.

*“A problem in this setting is bigger, yes for example when he stops breathing...” (P12)*

Participation in care, solving and handling problems concerning daily care however was considered important by all participants.

In the part of the questionnaire: About your child’s services, services were consequently referred to as medical, provided by professionals. Most participants expressed difficulties in making decisions when concerning medical care, however deciding about decisions concerning daily care seemed feasible by all participants.

*“Service I see as in medical decisions, and looking at nurses and their services, I can think about that services or about basic care my child needs” (P6)*

Furthermore, some of these items were described as not applicable and confronting parents with their helplessness and inability to participate. Item 6: “*I believe I can solve problems with my child when they happen*”.

*“And furthermore they are unable to solve the problem, because they do have a real help question” (N4)*

The item “*I feel I am a good parent*” was considered too confronting in the Dutch translation “*I find myself a good parent*”, therefore participants made suggestions for modification, based on importance of the item.

More than 6 participants, parents and nurses, expressed problems with applicability and comprehensibility in the other five items, (see Table 1). Items 2 and 8, investigating parents ability in supporting growth and development, were considered confronting and not applicable in this setting.

*“They learn things to support their child but growth and development is not yet relevant” (N2)*

*“When my child is critically ill I don’t consider whether he will learn to ride a bike in time....” (P19)*

In item 4, concerning family life, problems were expressed with applicability in this population.

*“With a family you really think of an existing family. Where everyone has its place and some older children maybe but in our situation that’s really premature..” (P12)*

### **Converging results**

Interpretations and identified problems from interviews, were weighed with outcomes of the Item Content Validity Index (I-CVI), and discussed. Nurses were more consistent regarding comprehensiveness and relevance of items, than parents.

Problems with applicability of items concerning problems or services in eight items, were confirmed by participants’ comments made on the study version of the FES questionnaire. I-CVI’s of these items ranged from .52 – .70. Only item 13, parents right to approve services delivered, scored an I-CVI of .84. Interview outcomes explained these low scores of relevance, as based on interpretation of services and problems as medical, and therefore not feasible for parents.

Items concerning knowledge, one of the expressions of empowerment, (see Table 3), in information sharing and regular contact with professionals, were considered important in interviews and relevant by parents, parents I-CVI  $\geq$  .85. Nurses I-CVI scores ranged from .27 - .82 in these items, which resulted in an I-CVI total  $\leq$  .77, irrelevant, for six items. In contrast to their scores on relevance nurses referred to information sessions, where parents

learn to interpret infants' signals, as contributing in gaining control over the situation. In item 5:

*"Who learns a lot about what an infant can say with certain signals" (P12)*

*"I think you can tell parents a lot and they are eager to know..." (N12)*

These items were, although irrelevant, considered important for determining parental empowerment in a NICU.

Participants expressed sharing information and partnership with professionals of great importance hereby supporting the relevance of items 5, 14 and 18, I-CVI's .81, .87 and .97 respectively.

Item 2, *"I feel confident in my ability to help my child grow and develop"*, was considered not applicable and confrontational in this setting. However based on relevance, total I-CVI .84 and a substantial higher I-CVI score for parents, namely 1,0 versus nurses .55, this item is considered applicable after modification.

The introduction of the study version substantially differed from the introduction of the translated FES. The concept of empowerment and an explanation of the two levels of empowerment, the context, as described in the introduction of the study version, was considered important by participants, to properly complete the questionnaire.

## **Discussion**

This study showed that, based on relevance, the Dutch translation of the FES seemed insufficient to measure empowerment in parents of infants admitted to a NICU. Interview data gave insight in problems and interpretations of items, explaining low scores of relevance. Converging outcomes showed opportunities to adapt this translated FES in order to make it feasible for use in a NICU.

Interviews provided participants with the opportunity to express their feelings and concerns regarding the items, without limitations regarding answering options. As described by Knafl et al (2007) and Beatty et al (2007), the thinking aloud method used for this interviews, gave the interviewer inside in reflections of the participants<sup>33,34</sup>.

In this study parents and nurses were considered experts on family empowerment. However no conclusive findings in literature endorsed this choice for experts. Van Kooten et al (2016), who used a panel of professional experts and participants of the target population, considered the opinion of professionals the most important<sup>39</sup>. In contrast to Polit et al (2007) who recommended input of the target population<sup>30</sup>. And while judging relevance of items in

Patient Reported Outcome Measures, Mokkink et al (2010) also considered patients to be experts<sup>25</sup>.

During the interviews parents described feelings of helplessness, inability to make decisions and solving problems, probably due to the stressful situation they were experiencing. This might have influenced their opinions and thereby their expertise. Based on remarks in the questionnaires and interviews, nurses acknowledged these parental feelings of stress. Higman et al (2008) also described these parental feelings and behavior in their study<sup>8</sup>. It is unclear if this knowledge concerning parental stress influenced nurses, and thereby their scoring of item relevance. However nurses' I-CVI scores were notably lower than parent scores, (see Table 3).

Participants defined problems with instructions to complete the questionnaire, the absence of a clear introduction and lack of knowledge on the concept of empowerment. Explanation of the aim of the questionnaire, the concept of empowerment and the context for assessing the items was considered essential for parents to complete the questionnaire properly. Therefore this needs further investigation. Withers et al (2015), also investigated instructions as part of content validity in their questionnaire<sup>40</sup>.

The FES is used in many countries and populations, e.g. studying parents of children with disabilities, emotional and behavioral disorders<sup>41,42</sup>. However no studies, using the FES, were found assessing family empowerment in a NICU. The lack of parental or family feelings and behavior, as described by Finlayson et al (2014), and endorsed by our findings, might explain the choice for studying empowerment in a NICU using other measurement instruments, like the NICU Parent Belief Scale (NICU-PBS)<sup>1,43,44</sup>

Parents however, expressed their need for information, involvement in decision making, and taking over their parental role. Furthermore all participants subscribed the need to empower parents to provide complex care, support their infant and improve wellbeing. Peyrovi et al (2016) and Brett et al (2010) confirmed this need to empower parents in their studies<sup>5,45</sup>. By acknowledging this importance of empowerment, and especially the necessity to increase parental empowerment, the need for an instrument to measure the effect of interventions empowering parents, is present. Several studies, Melnyk et al (2001), Melnyk et al (2006), and Gonya et al (2014), measured the effect of empowerment strategies as the Creating Opportunities for Parent Empowerment program (COPE©) in the NICU<sup>43,44,46</sup>. Based on our findings, and the proven reliability and validity of the FES to measure family empowerment, adjusting this FES could provide NICU professionals with an instrument to study effectiveness of empowerment strategies.

Using mixed methods in evaluating content validity, and comparing and discussing all data by two researchers, to make clear recommendations regarding content validity of the

FES, strengthened our study. Qualitative data gave insights in the concept of empowerment, as experienced in this population.

Selection bias, as described below, might have influenced and thereby limited our findings. No literature was found to confirm the educational level in our study, >75% of parents was bachelor or higher educated in our sample, to be representative for this population. On beforehand a purposeful sampling method, based on heterogeneous outcomes of I-CVI, was preferred for the interviews. However due to early transfer, a convenient sampling approach turned out to be more feasible.

Approaching parents > 48 hours after admission, might have been too soon, and thereby overwhelming for parents, considering their expressed feelings of stress. Although some parents considered participation, they lacked time and concentration to read the information letter and failed to participate.

### **Conclusions**

This content validity study revealed the importance of empowerment and evaluation of this process in the NICU, hereby subscribing the need for an instrument to measure empowerment. Although adjustments are required, our study showed suitability of this translation of the FES in the NICU. Based on reliability and validity of the FES in covering the concept of empowerment, preserving the construct of the questionnaire is important. We recommend to adjust the introduction of the FES, in accordance with the study version, to explain the aim and the context in which the questionnaire is related. Furthermore customizing items, by using participants' recommendations, to fit the population is necessary. To establish content validity of this adjusted FES in a population of parents and nurses in a NICU, further research, using mixed methods, is recommended.

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## Tables

Table 1; Summarization of interviews

<b>Items</b>	<b>Q1</b> When problems arise with my child I handle them pretty well <b>(a)</b>	<b>Q2</b> I feel confident in my ability to help my child grow and develop <b>(b)</b>	<b>Q3</b> I know what to do when problems arise with my child <b>(a)</b>
<b>Interpretations</b>	Problems are interpreted as medical. Inability for parents to handle medical problems in this setting. Unclear for participants whether the item focuses on family life.	Parents and professionals express growing and development as issues parents are not concerned with yet in this setting. Parents experience uncertainty concerning these issues and therefore less relevant	Problems are referred to as medical, parents are unable to act when these problems occur. Not suitable in this setting with focus on medical problems. Similarity with question 1.
<b>Problem Type</b>	Interpretability, clarity, comprehensiveness. Applicable if problems are referred to as medical.	Applicability in this setting, relevance. Confronting for parents.	Applicability in this setting, relevance, wording of problems unclear, interpretability.
<b>Items</b>	<b>Q4</b> I feel my family life is under control <b>(b)</b>	<b>Q5</b> I am able to get information to help me better understand my child <b>(c)</b>	<b>Q6</b> I believe I can solve problems with my child when they happen <b>(a)</b>
<b>Interpretations</b>	Participants state they experience loss of control during admission to a NICU. Family life is not acknowledged by parents. Parents might become uncertain answering this question. Applicable in case of children at home	Gaining information concerning their child is acknowledged to be important to all participants. Clear question relevant in this setting, two participants experienced difficulties understanding. Referred to information sessions, flyers and in person by professionals.	Comprehensibility of problems, which problems are referred to. Problems concerning daily care are solvable for parents. Question confronts parents with their feelings of helplessness in a NICU. Same question as number 1
<b>Problem Type</b>	Applicability	No problems	Interpretability of problems, confronting for parents
<b>Items</b>	<b>Q7</b> when I need help with problems in my family I am able to ask for help from others <b>(c)</b>	<b>Q8</b> I make efforts to learn new ways to help my child grow and develop <b>(b)</b>	<b>Q9</b> When I am dealing with my child I focus on good things as well as the problems <b>(a)</b>

<b>Interpretations</b>	Comprehensible question, “others” multi interpretable, but concerned of no problem. Good question	Comprehensible question but not applicable in this setting. Growing and developing are issues parents are not concerning yet. Might cause uncertainty in parents, inability to influence the situation.	Comprehensibility of the question, aim of the question not clear. The focus on good things or on problems, answers difficult to interpret what are parents focusing on? Focus on good things acknowledged as important.
<b>Problem Type</b>	Wording of “others”	Applicability and confronting	Interpretation, comprehensiveness
<b>Items</b>	<b>Q10</b> When faced with a problem concerning my child I decide what to do and then do it <b>(a)</b>	<b>Q11</b> I have a good understanding of my child’s disorder <b>(a)</b>	<b>Q12</b> I feel I am a good parent <b>(a)</b>
<b>Interpretations</b>	Comprehensible question, but unclear what problems to focus on. Applicable when concerning problems in daily care. Parents are able to decide when problems occur concerning daily care. Fits empowerment.	Comprehensible question, suitable and important in this setting. Disorder poorly worded, prematurity not considered as a disorder. Understanding of the situation helps parents to gain control and certainty	Comprehensible and important in this setting. Too strictly worded, ( <i>In Dutch: I find myself a good parent</i> ) . Could cause uncertainty in parents.
<b>Problem Type</b>	Interpretability of problems. Medical problems not feasible. Applicability	Wording of disorder	Wording and confronting
<b>Items</b>	<b>Q13</b> I feel that I have the right to approve all services my child receives <b>(a)</b>	<b>Q14</b> I know the steps to take when I am concerned my child is receiving poor services <b>(c)</b>	<b>Q15</b> I make sure professionals understand my opinions about what services my child needs <b>(a)</b>
<b>Interpretations</b>	Comprehensible and clear question, this right is acknowledged by all participants. Applicability in this setting difficult. Feels inappropriate not to approve of services delivered, focus on medical services.	Relevant and clear question, comprehensible. Applicable in this setting.	Comprehensibility, some participants experienced difficulties understanding the question. “I make sure” too explicit formulated. Little relevance in case of medical care.
<b>Problem Type</b>	Too explicit formulated, feasibility	No problems	comprehensiveness and feasibility

<b>Items</b>	<b>Q16</b> I am able to make good decisions about what services my child needs <b>(a)</b>	<b>Q17</b> I am able to work with agencies and professionals to decide what services my child needs <b>(a)</b>	<b>Q18</b> I make sure I stay in regular contact with professionals who are providing services to my child <b>(c)</b>
<b>Interpretations</b>	Interpretability of services as medical. Parents are unable to make decisions concerning medical services. Applicable and relevant when concerning daily care	Comprehensibility and applicability of agencies in this setting unclear. Working with professionals acknowledged to be important.	Comprehensible and important in this setting
<b>Problem Type</b>	Interpretability and thereby applicability. Same question	Wording of agencies, feasibility	No problem
<b>Items</b>	<b>Q19</b> My opinion is just as important as professional's opinions in deciding what services my child needs <b>(a)</b>	<b>Q20</b> I tell professionals what I think about services being provided to my child <b>(c)</b>	<b>Q21</b> I know what services my child needs <b>(a)</b>
<b>Interpretations</b>	Opinion of professional's considered to be of more importance. Services referred to as medical. When concerning daily care the opinion of parents is considered to be of equal importance.	Comprehensible and considered important. Contributes to a feeling of empowerment. In case of medical care parents lack knowledge. Weekly planned evaluations provide parents with the possibility to act so. Confronting .	Interpretation of services, applicable if concerning daily care. Contributes to empowerment.
<b>Problem Type</b>	Interpretation and wording of services	Feasibility, interpretation services	Wording, interpretability of services.
<b>Items</b>	<b>Q22</b> When necessary, I take the initiative in looking for services for my child and family <b>(b)</b>	<b>Q23</b> I have a good understanding of the service system that my child is involved in <b>(b)</b>	<b>Q24</b> Professionals should ask me what services I want for my child <b>(a)</b>

**Interpretations**

Diverse interpretations, some parents link this question to other children at home. Not applicable in this setting, services are delivered. Initiative links to empowerment

Comprehensibility, wording of services system. Services system is associated with health assurance, and there for not applicable in this setting.

Services too broadly defined. Relevant concerning daily care. Parents initiative should fit empowerment more.

**Problem Type**

Relevance in this setting and feasibility

Comprehensibility and applicability

Wording of services.

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Note. Reference to outcomes of comprehensiveness: **(a)** Problems with interpretability, clarity, wording and/or tone of items;**(b)** Problems with applicability and comprehensibility of items by more than 6 participants; **(c)** Items considered comprehensible and applicable.

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Table 2. Baseline characteristics of participants.

<b>Characteristics parents</b>	<b>QUAN N=20</b>	<b>QUAL N=9</b>
Gender parent : N (%)		
Female	12(60)	5(55,6)
Age in years: mean ( $\pm$ SD);(range)	31,7(3,9);(21-40)	29,3 (4,0);(21-33)
Marital state : N (%)		
Married	14 (70)	6(66,7)
Living together	6 (30)	3(33,3)
Cultural background N (%)		
Dutch	19 (95)	9(100)
Not Dutch	1 (5)	
Educational level parent: N (%)		
Trade school	5 (25)	2(22,5)
Bachelor's degree	4 (20)	1(11,1)
Master's degree	11 (55)	6(66,7)
Other children in family : N (%)		
yes	5 (25)	3(33,3)
no	15 (75)	6(66,7)
Gender child: N (%)		
male	14 (70)	4(44,4)
Gestational age in weeks(w),days(d) ;median ( $\pm$ SD) (range)	30(w),1(d);(3w5d) (24w3d-39w1d)	29(w)3(d);(1w4d) (26w6d-31w1d)
Birth weight in grams: mean ( $\pm$ SD)(range)	1485 (760) ( 335-3060)	1275 (443) (335-1880)
Length of stay in days : median ( $\pm$ SD)(range)	8,5 (19,3)(2-78)	8 (2)(6-12)
<b>Characteristics Nurses</b>	<b>QUAN N=11</b>	<b>QUAL N=4</b>
Gender nurses N (%)		
Female	10 (91)	3 (75)
Age in years mean ( $\pm$ SD) (range)	42 (7,5) (29-52)	40,5 (5,1) (33-44)
Educational level nurses N (%)		
Trade school	9 (81,8)	3 (75)
Bachelor's degree	2 (18,2)	1 (25)
Experience in years mean ( $\pm$ SD) (range)	19,7 (8,7) (8-33)	18,6 (5,8) (10-22)
Employment NICU in years mean ( $\pm$ SD) (range)	14 (8,6) (2-28)	10,8 (7,5) (2-17)
Service rate mean ( $\pm$ SD) (range)	0,80 (0,15) (0,67-1,1)	0,79(0,21)(0,66 -1,1)

Table 3. I-CVI outcomes

	Expressions empowerment	I-CVI parents	I-CVI Nurses	I-CVI Total
Q1 When problems arise with my child I handle them pretty well	Behaviours	0,80	0,46	0,68
Q2 I feel confident in my ability to help my child grow and develop	Attitude	1,0	0,55	0,84*
Q3 I know what to do when problems arise with my child	Knowledge	0,90	0,27	0,68
Q4 I feel my family life is under control	Attitude	0,75	0,46	0,65
Q5 I am able to get information to help me better understand my child	Knowledge	0,90	0,64	0,81*
Q6 I believe I can solve problems with my child when they happen	Attitude	0,75	0,36	0,61
Q7 When I need help with problems in my family I am able to ask for help from others	Knowledge	0,85	0,78#	0,83#
Q8 I make efforts to learn new ways to help my child grow and develop	Behaviours	0,65	0,64	0,65
Q9 When dealing with my child, I focus on the good things as well as the problems	Behaviours	0,75	0,64	0,71
Q10 When faced with a problem involving my child, I decide what to do and then do it	Behaviours	0,65	0,27	0,52
Q11 I have a good understanding of my child's disorder	Knowledge	0,95	0,73	0,87*
Q12 I feel I am a good parent	Attitude	0,70	0,67#	0,69#
Q13 I feel that I have a right to approve all services my child receives	Attitude	0,90	0,73	0,84*
Q14 I know the steps to take when I am concerned my child is receiving poor services	Knowledge	0,90	0,82	0,87*
Q15 I make sure that professionals understand my opinions about what services my child needs	Behaviours	0,85	0,40**	0,70**
Q16 I am able to make good decisions about what services my child needs	Knowledge	0,90**	0,36	0,70**
Q17 I am able to work with agencies and professionals to decide what services my child needs	Knowledge	0,95	0,27	0,71
Q18 I make sure I stay in regular contact with professionals who are providing services to my child.	Behaviours	1,00	0,91	0,97*
Q19 My opinion is just as important as professional's opinions in deciding what services my child needs	Attitude	0,80	0,36	0,65
Q20 I tell professionals what I think about services being provided to my child	Behaviours	0,75	0,82	0,77
Q21 I know what services my child needs	Knowledge	0,85	0,36	0,68
Q22 When necessary, I take the initiative in looking for services for my child and my family	Behaviours	0,90	0,46	0,74
Q23 I have a good understanding of the service system that my child is involved in	Knowledge	0,90	0,55	0,77
Q24 Professionals should ask me what services I want for my child	Attitude	0,70	0,27	0,55

Note : \* I-CVI  $\geq 0,78$ , considered good content validity; # corrected outcome complete case analysis, however based on >5% missing data therefore considered irrelevant

\*\*Corrected outcome complete case analysis,  $\leq 5\%$  missing data.

## Appendix

### Appendix A

#### 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) te beïnvloeden 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 relevant zijn in een vragenlijst waarmee we empowerment van ouders met een 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

<b>13</b>	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"/>				
<b>14</b>	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"/>				
<b>15</b>	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"/>				
<b>16</b>	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"/>				
<b>17</b>	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"/>				
<b>18</b>	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"/>				
<b>19</b>	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"/>				
<b>20</b>	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"/>				
<b>21</b>	Ik weet welke zorg mijn kind nodig heeft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<b>22</b>	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"/>				
<b>23</b>	Ik begrijp het zorgstelsel rondom mijn kind goed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<b>24</b>	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 B

### Interview guide

Type cognitieve probe vraag	Probe vragen
Begrijpelijkheid en interpretatie	<ul style="list-style-type: none"><li>• Wat betekent de term empowerment voor u?</li><li>• Wat denkt u bij deze vraag?</li></ul>
Duidelijkheid van de items	<ul style="list-style-type: none"><li>• Kunt u de vraag in uw eigen woorden herhalen?</li></ul>
Specifiek	<ul style="list-style-type: none"><li>• Waarom zegt u dat het belangrijk is?</li></ul>
Algemeen	<ul style="list-style-type: none"><li>• Hoe komt u op dat antwoord?</li><li>• Was het makkelijk of moeilijk te beantwoorden?</li><li>• Ik zag dat u aarzelde, kunt u me vertellen wat u dacht?</li><li>• Kunt u me daar meer over vertellen?</li><li>• Zijn er woorden of omschrijvingen die u zou willen veranderen?</li></ul>
Vragen omtrent de vragenlijst in zijn algemeen	<ul style="list-style-type: none"><li>• Welke andere ervaringen heeft u met empowerment die niet gevraagd worden in deze vragenlijst?</li><li>• Zijn er ook andere punten waar u aan denkt bij empowerment en niet worden genoemd in deze vragenlijst?</li></ul>
Vragen omtrent vragenlijst om te bepalen of de participant moeite heeft met de presentatie van de vragenlijst.	<ul style="list-style-type: none"><li>• 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.</li><li>• Welke suggesties heeft u om de vragenlijst te veranderen om deze makkelijker in te kunnen vullen?</li></ul>