# **Master Thesis**

Content validity of the Distress Thermometer for Parents. assessed by health care professionals within the Neonatal Intensive Care Unit

Carin (C.W.) Dansen

Student number 6371531

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Supervisor Dr A. van den Hoogen

University Medical Centre Utrecht - Division woman & child

Mentor UU Dr J.F.M van Dijk

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#### **Abstract**

**Background**: In the Netherlands, 11.210 live born infants were delivered prematurely (before 37 weeks gestational age) in 2017. of which 15% were admitted to the neonatal intensive care unit (NICU). Premature delivery is stressful for parents, thus. monitoring parents at the NICU is essential for timely detection of psychosocial problems. The Distress Thermometer for Parents (DT-P) was developed to assess psychosocial functioning for parents with a chronically sick child. In order effectively to use the DT-P for parents of neonates at NICUs content validation is necessary.

**Aim**: The current study investigates content validity on relevancy and comprehensiveness of the DT-P from the perspective of NICU healthcare professionals.

**Methods**: A cross-sectional, descriptive, and prospective study was conducted. A survey was used to assess 42 DT-P items on relevance and comprehensiveness by NICU healthcare professionals in the Netherlands. The Content Validity Index (CVI) and the average of proportion items (S-CVI/Ave) of each DT-P item was measured by a 4-point Likert scale.

**Results**: Of the 70 survey's, 51 were retrieved completed. Thirty items(71.4%) related to relevance met the 'excellent' criteria, with scores above 0.779 (range 0.78-0.96). The S-CVI/Ave's concerning relevance were 0.81 and 0.79. Regarding the content validity of comprehensiveness, merely 23 of 42 items (55%) scored excellent (range 0.78-0.92). and both S-CVI/Ave's amounted to 0.77.

Conclusion: The DT-P's content validity was assessed on relevance by healthcare professionals from Dutch NICU wards. With the results of current quantitative research, content validity appears to have been achieved on relevance but not on comprehensiveness. Implications of key findings: This analysis is a first step in identifying healthcare professionals' perspectives towards the use of the DT-P as a fast screening instrument. Additional qualitative research is essential to capture in-depth meaning towards given ratings.

Keywords: Distress Thermometer (for Parents), parental distress, NICU healthcare professionals, content validity.

#### **SAMENVATTING**

Achtergrond: In 2017 werden in Nederland 11.210 levende zuigelingen te vroeg geboren (vóór de zwangerschapsduur van 37 weken), waarvan 15% werd opgenomen op de neonatale intensive care unit (NICU). Een vroegtijdige bevalling wordt als stressvol ervaren door ouders. Het observeren van ouders op de NICU is essentieel om psychosociale problemen tijdig op te sporen. De Lastmeter voor Ouders (LTO) is ontwikkeld om het psychosociaal functioneren van ouders van een chronisch ziek kind snel en effectief te beoordelen. Om de LTO effectief te gebruiken voor ouders van pasgeborenen opgenomen op NICU's dient deze gevalideerd te worden op inhoud.

**Doel**: De LTO valideren op inhoudsvaliditeit door NICU-zorgprofessionals, voor ouders van prematuren opgenomen op de NICU.

**Methode**: Een cross-sectioneel prospectief beschrijvend onderzoeksontwerp werd uitgevoerd. Enquêtes werden gebruikt om 42 DT-P items te beoordelen op relevantie en volledigheid door NICU zorgprofessionals in Nederland. De inhoudsvaliditeitsindex en het gemiddelde van het aantal beoordeelde items (S-CVI/Ave) van elk DT-P item werd gemeten middels een 4-punts Likertschaal.

**Resultaten**: Van de zeventig enquêtes werden 51 ingevuld en geretourneerd. Dertig van de items op relevantie (71%) werden als 'excellent' beoordeeld, met scores boven de 0.779 (bereik 0.78-0.96). De bijbehorende S-CVI/Ave's bedroegen 0.81 en 0.79. Met betrekking tot de inhoudsvaliditeit gerelateerd tot volledigheid, scoorden slechts 23 items (55%) uitstekend (bereik 0.78-0.92), en beide S-CVI/Ave's bedroegen 0.77.

**Conclusie**: De validiteit van de DT-P werd als uitstekend beoordeeld aangaande de relevantie, maar onvoldoende op volledigheid.

**Aanbevelingen**: Met deze analyse werd een eerste stap gezet om het perspectief van zorgprofessionals ten aanzien van het gebruik van de DT-P als een snel screeningsinstrument, in beeld te brengen. Aanvullend kwalitatief onderzoek is nodig om een diepere betekenis te geven aan de scores.

Trefwoorden: Lastthermometer(voor ouders), psychische nood van ouders, NICU-zorgprofessionals, inhoudsvaliditeit.

#### INTRODUCTION

Worldwide, approximately 1 in 10 infants are born prematurely (before 37 weeks gestational age [GA]).<sup>1,2</sup> In 2017, a total of 11.210 live infants were born prematurely in the Netherlands, of which 15% were admitted to the neonatal intensive care unit (NICU) for more than one day.

Most of the infants' parents experienced various negative feelings during their child's stay on the NICU, including stress, anxiety, and adverse feelings related to the birth not going as anticipated.<sup>3,4</sup> Following this stressful event, parents are expected to adjust their parenting style and coping strategies to the limitations imposed by NICU admittance. The natural bonding and attachment process differs from what is considered the optimum<sup>3,4</sup> due to the presence of tubes, lines, and machines. These parents must adjust their approach to parenting to their vulnerable infants, while physical contact is limited or restricted. Approximately 23–28% of parents may develop symptoms that precede psychosocial problems.<sup>3–9</sup> The loss of their parental role (e.g., because of separation) is an important factor in the perceived stress.<sup>4</sup> Parents may have specific needs,<sup>10</sup> including accurate information, cooperation with and to feel welcomed by NICU staff, and above all, personalised and the feeling of trustworthy care for their infant. These needs can be met through effective communication and appropriate anticipatory guidance.<sup>4</sup> Any lack of clarity in communication with and/or actions towards the parents can complicate infants' daily care. Therefore, it is essential to screen parents during and after their infant's hospitalisation, to visualise the experienced burden and, to prevent psychosocial problems in these parents at an early stage.5-7

Different screening tools were considered including the, Creating Opportunities for Parent Empowerment (COPE)<sup>11</sup> and the Guided Family-Centred Care (GFCC) programmes, 12.13 but neither support programmes seems suitable as a fast screening instrument for screening psychosocial problems in parents. Similarly, the Parental Stressor Scale: Neonatal Intensive Care (PSS: NICU)<sup>14,15</sup> focusses on problems with the surroundings at the NICU and not on broader problems (e.g., practical problems at home). The Distress Thermometer for Parents (DT-P) seems to be the most suitable choice to investigate on its content validity as a fast screening instrument for measuring psychosocial care needs of NICU parents at an early stage. 16.17

The DT-P<sup>16</sup> originated as the widely used Distress Thermometer (DT).<sup>18,19</sup> The DT was developed by the National Comprehensive Cancer Network<sup>18-21</sup> as a simple monitoring list for quickly and effectively assessing the psychosocial functioning. Moreover, the DT should promote communication between healthcare professionals and its patients undergoing cancer treatment. The DT was validated worldwide as a fast screening instrument in 2014,<sup>21</sup> which enabled healthcare professionals to provide systematic parental CW Dansen 4 Content Validity study care as a team. The DT was translated to Dutch in 2004,<sup>18</sup> validated in 2008<sup>22</sup>, and is now used in hospitals across the Netherlands. Since implementation of the DT, communication between healthcare providers and cancer patients has been improved.<sup>18,19</sup> A previous study,<sup>16,17</sup> adjusted and validated the DT to identify parents who experience or are at risk of psychological distress when coping with a chronically ill child and added the P to the acronym. The DT-P consists of a thermometer score from 0 (no distress) to 10 (extreme distress) and a problem list with potential stressor areas (practical, social, emotional, physical, cognitive, and parenting domains).<sup>16,18,19</sup>

The results the DT-P provides as a screening instrument could aid in early detection

of potential psychosocial problems, contributing to optimisation of structured medical care. For parents with children admitted to the NICU, this tool can provide a method of self-reflection and improve towards the feeling of self-empowerment.

However, validation is needed to determine whether this screening instrument could be effectively used in the parents of NICU infants. Validation is needed to retrieve clinically relevant results. There are five types of validity: face, content, construct, criterium, and external.<sup>23</sup> The current analysis focusses on content validity, which is defined as 'The degree to which an instrument has an appropriate sample of items for the construct being measured'.<sup>24–26</sup> Thus, to investigate whether the DT-P adequately reflects the distress levels in parents of NICU infants, content validity is crucial to assess.<sup>27</sup> Content validity can be obtained with the COnsensus-based Standards for the selection of the health Measurement INstruments (COSMIN) criteria.<sup>28,29</sup> This methodological manual has the framework of assessing healthcare professionals' expert opinion, which can be applied on all items of the DT-P on item and scale level.

## **Aim**

Current study investigates the content validity, on relevancy and comprehensiveness of the DT-P from the perspective of NICU healthcare professionals to detect symptoms of psychosocial problems of parents at an early stage. These findings can potentially drive improving parental care.

#### Methods

## Design

A cross-sectional, descriptive, and prospective design was used. The cross-sectional design aimed to capture healthcare professional's perceptions of the validity of the DT-P at a single time point.<sup>26,30</sup> An online survey tool was used to investigate the original items of the DT-P.

# **Population**

The current analysis was conducted in five academic hospitals and two general hospitals in the Netherlands. The study population consisted of healthcare professionals working in an NICU or in areas directly related to the NICU, including: nurses, doctors, speech therapists, social workers, psychologists, pastoral assistants, remedial educationalists and physician assistants. Healthcare professionals were eligible for this study if they worked for at least one year with parents at an NICU and were employed by one of the (academic) hospitals with an NICU in the Netherlands. A healthcare professional was excluded if they were: seconded personnel (e.g. working through an employment agency) or unable to read and speak Dutch (e.g.an exchange student). According to the COSMIN criteria, <sup>29,34,35</sup> the participation of more than 50 experts provides an outcome that is representative of the target population

#### **Procedures**

In December and January 2021, NICU managers were approached by the researcher through email inviting their NICU to participate in this study. An information letter and a table providing an indication of the desired professions and number of healthcare professionals needed for this study were sent included. The manager contacted eligible participants and, after confirmation, email addresses were sent to the researcher. If no response was received after a month, a reminder was sent.

Simultaneously, a survey was developed that included the questions from the DT-P. The participants were asked to provide informed consent, demographic data(e.g. age, gender, profession, years of employment and, ethnicity) and answer several questions related to the relevance and comprehensiveness (on a 4-point Likert scale) of the DT-P. A pilot was performed with six healthcare professionals to evaluate the clarity, instructions and time needed to fill in the survey, after which adjustments were made.

## **Data Collection**

Participants' email addresses were coded anonymously in the online survey.<sup>33</sup> The researcher could review the progress of each survey online. Completed surveys were locked and transported to the International Business Machines Corporation Statistical Package for the Social Sciences version 26 (SPSS)<sup>34</sup> for analysis. If, after two weeks, no completion was detected, a re-invite was automatically to obtain as many completed surveys as possible.

The primary study parameter was the content validity represented by the Content Validity Index (CVI). The CVI is the most widely used method to quantify content validity for multi-item scales in nursing research.<sup>24,25,33</sup> <sup>25</sup>Advantages of using the CVI include its understandability and the focus on relevance rather than agreement.<sup>25</sup> Content validity is measured on item level (I-CVI) and scale-level based on the average method (S-CVI/Ave).<sup>23–</sup>

<sup>25.33</sup> In compliance with the COSMIN criteria, <sup>29.34.35</sup> the relevance and comprehensiveness of all items were scored by NICU healthcare professionals. The relevance of a screening tool refers to the appropriateness of its elements in measuring the targeted constructs and functions of assessment. <sup>23.28.29</sup> Comprehensiveness refers to whether all included items are applicable to the domain (stressor area) provide an encompassing.

The CVI<sup>24,25,33</sup> of each DT-P item was measured by a 4-point ordinal Likert scale (1 = not relevant/complete, 2 = somewhat relevant/complete, 3 = quite relevant/complete and, 4 = highly relevant/complete).<sup>28,29</sup> The use of this scale avoids retrieving a neutral result. After dichotomising it is possible to formulate a recommendation, I-CVI is formulated as (agreed item)/(number of experts). The definition of an agreed item is a rating of 3 or 4.

The S-CVI/Ave was defined as 'the average of the I-CVI scores for all items on the scale or the average of proportion relevance judged by all experts'. Further, the proportion relevance was determined by 'the average of relevance rating by an individual expert'. The formulas used were the following:

S-CVI/Ave (items) = (sum of I-CVI scores)/(number of items).

S-CVI/Ave (experts)= (sum of proportion relevance ratings)/(number of experts).

Formulas are further specified in Table 1. Both definitions and calculations were based on the recommendations by Polit and Beck<sup>24,25,35</sup> and by Lynn.<sup>36</sup>

#### Insert Table 1

The DT-P consists of 42 items across six different domains (practical, social, emotional, physical, cognitive, and parenting domains). After peer review of all DT-P items, the research divided the original parenting domain into three domains: approach to parenting after a child's discharge from the hospital, support from family, friends and healthcare professionals and, additional items. These adjustments were made in an attempt to emphasise the structure of the DT-P towards this population. Thus, all original DT-P items were restructured in a logical order for NICU parents. No items were added, a few items which were not applicable for parents of NICU children were removed. These divisions provide better captured of all psychosocial aspects playing a role in the wellbeing of NICU parents.

The second study parameter encompassed demographic data (age, gender, profession, years of employment, ethnicity). The baseline characteristics provide insight into the composition of the sample.<sup>37</sup>

The complete questionnaire contained 84 questions, of which 42 on relevance and 42 on comprehensiveness. In case a questionnaire showed more than 8% missing data computation were applied. In this case, missing values are considered missing completely at random.

# **Data Analysis**

Firstly, descriptive statistics were used to understand the participants' background and professional characteristics. Participants' backgrounds consisted of age and years of employment and were, described as continuous variables with a standard deviation and median. Gender (male/female), profession (those listed above in population) and ethnicity (country of origin and nationality) were, described as categorical variables with frequencies and percentages.<sup>38</sup> Participants are defined as expert opinions on the subject because of their professional expertise.

The 4-point Likert scale scores were dichotomised as 1 (relevance rating of 3 or 4) and 0 (relevance rating of 1 or 2) since: only ratings of 3 and 4 on relevancy and completeness were considered essential for this analysis. <sup>26,36,39</sup>

Polit and Beck,<sup>24–26</sup>are considered important founders for the calculation of the CVI. Content validity was deemed excellent when participants score 78% or higher on I-CVI. Their lower limit criterion of the S-CVI/ Ave is considered acceptable when exceeding 0.80, while a S-CVI/Ave of 0.90 is preferred by scale developers.<sup>36</sup>

Changing and adapting the content of the DT-P was not part of this study. Possible recommendations will be transferred, after completion of this study, to the developers of the DT-P. The descriptive statistics analyses were performed using SPSS syntax.

#### **Ethical issues**

The study was conducted according to the principles of the Declaration of Helsinki. <sup>40</sup> The Medical Research Involving Human Subjects Act (WMO) was not applicable since participants were merely asked to complete a survey. <sup>41</sup> The participants could only proceed with the survey if informed consent was given. A non-WMO statement was given by the Medical Ethics Research Committee of the University Medical Center Utrecht for this project (21-108/C). A data management plan was made to provide a safe and transparent representation of the steps made to secure the data according to the University regulations. All data were collected and handled according to the General Data Protection Regulation (GDPR). <sup>42</sup> Monitoring was done by the post doc and senior researcher AH, and experts in the field.

#### Results

## **Participants**

The estimated time for healthcare professionals to complete the survey at home or at work, was 20-30 minutes. In total, 70 surveys were sent, and 51 surveys were retrieved back completed (response rate of 72.8%). No missing data in participants' baseline characteristics were shown. On item level ratings on relevance and comprehensiveness of the 51 participants, 12 (17%) contained missing data, with a range of 1-4 missing answers

across 84 items. With this range of missing data, imputation methods were not applied. One of the 70 participants (1.4%) only filled in the demographic parameters. This survey was excluded from analysis. Seventeen surveys (24.3%) were not returned. One participant only answered the questions on relevancy. This survey was included in the relevance analysis because the answers were still valid in assessing relevance while imputation for the complete list on comprehensiveness could not be statically justified by the researcher.

## **Baseline/Demographic Data**

Demographics are presented in Table 2.0f 51 participants, 40 (78.4%) were female. The mean age of the participants was 43.8 years (SD 11.0). The average time of employment was  $16.5 \pm SD$  11.9 years.

## Insert Table 2

# **Content Validity Index on the DT-P**

In 71.4% (n=30) of the items on relevance the 'excellent' criteria<sup>36</sup> was met, with scores above 0.779 (range 0.78-0.96). The S-CVI/Ave(experts) was 0.81 and the S-CVI/Ave(items) was 0.79. The domains of physical and cognitive problems scored below the cut-off point (more than 0.78). On Item level, interacting with friends(0.59), sleeping problems (0.39), fatigue (0.29), sexuality (0.47), forgetfulness (0.43),scored far below the cut-off point.

Regarding the content validity of comprehensiveness 23 items (55%) scored excellent (range 0.78-0.92). Notably, the domain of physical problems was rated as nearly complete(0.73). Both S/CVI-Ave's(experts) and S/CVI-Ave's(items) scored 0.77. Table 3 presents the I-CVI ratings with the cut-off score for excellence (scores under the cut-off point are depicted in orange font).

# Insert Table 3

In Table 4 I-CVI mean ratings in its corresponding domain are displayed. Six ratings on relevance and five on comprehensiveness showed values above the 0.78. The rating for the domain physical problems was 0.58.

## Insert Table 4

## Discussion.

## **Summarising Main Findings**

The current analysis focused on the content validity of relevancy and comprehensiveness of the DT-P from the perspective of NICU healthcare professionals. Fifty-one participants completed the survey, of which analyses was performed on 51 experts' view on relevance and 50 on comprehensiveness.

With regards to relevance, the S-CVI/Ave score was 0.81 on relevance, which is considered adequate but not excellent.<sup>36</sup> The domains of physical and cognitive problems scored below the cut-off point (more than 0.78). Regarding the content validity of comprehensiveness, 23 items (55%) scored excellent.

# **Comparison with Previous Literature**

The current analysis showed low relevance scores on the physical problems domain, which implies that NICU healthcare professionals are less focused on physical complaints of the parents of their NICU babies. One may question whether it is NICU healthcare professionals whom do not find physical problems in parents of importance. In addition, one may speculate that parents whom have a NICU child, are more likely to reprioritise their own physical health. To the best of our knowledge, there are no previous studies available which address this potential gap of the DT-P towards parental guidance. Due to the lack of previous studies on validation of the DT-P in parents of NICU babies by NICU healthcare professionals, comparison of current results with previous analyses was omitted. Current analysis utilised solely objective methods to assess content validity of the DT-P. For future research, inclusion of subjective, i.e., qualitative outcome measures is warranted to gain better understanding of the views of the NICU professionals on the added value of fast screening instruments including the DT-P, applied in the NICU setting. A mixed methods design would be appropriate to combine quantitative and qualitative assessments of such screening instruments.

The mixed methods design of Lotte et al.<sup>16</sup>, aimed to validate the DT-P by comparison of the DT-P results with the hospital anxiety and depression scale in parents of chronically sick children. Parents gave their scores related to relevance and comprehensiveness. Lotte et al.<sup>16</sup> provided insight into the importance of mapping parents' distress when there is a sick child and therefore in some extent linked to the current study.

The study of Withers et al,<sup>43</sup> also used a mixed methods design. In addition, the researcher verified whether the participant adequately understood what was expected of them (e.g., Has the information letter been read? Is the participant familiar with the concept of a fast screening tool?). This information helps to identify practical problems in application of such fast screening instruments. The COSMIN criteria confirm that additional qualitative research, e.g., by means of surveys, is important to gain full understanding of the results of the instrument.<sup>29,32</sup>

The POPPY Project <sup>44</sup> in British neonatal units identified gaps in the provision of psycho-social support for parents. Indeed, more than a quarter of parents were not offered any form of emotional support while their children were in the NICU. These findings, again, support that additional qualitative research is needed. In this case specifically, to verify whether healthcare professionals are aware of a potential gap in the services provided.

A fast screening instrument can provide more in-depth information for both parents and healthcare professionals. Parental' needs and experiences can evolve over time so help should be offered on several moments in time. Screening instruments like the DT-P could be applied for monitoring parents' wellbeing in different points of time. The stress of a premature birth can cause a barrier to seek help. These screening instruments might contribute to the feeling of empowerment in these parents. Future studies should assess whether the DT-P, or other instruments are effective as a method of self-assessment and reflection for parents prone to psychosocial problems.

## **Strengths & Limitations**

Polit and Beck,<sup>24–26</sup>are considered important founders for the calculation of the CVI. Their lower limit criterion of the S-CVI/ Ave is considered acceptable when exceeding 0.80. A 0.90 is preferred by scale developers, while 0.81 on relevance it is considered adequate but not excellent.

When using a Likert scale every item is assessed in a similar fashion, meaning that each item carries the same weight. Using a 4-point Likert scale meant that participants could not reply in an inconsistent way, 45 and by omitting a "neutral" option participants were forced reflect a less or more positive or negative option.<sup>30</sup> In this way, answers were dichotomised so that statements could be made. According to the COSMIN criteria, the 51 responses constitute a thorough reflection of the healthcare professionals' opinions on relevance and comprehensiveness. <sup>28,29,46</sup> Most of the advice suggested in Foundation of Clinical Research<sup>47</sup> was followed to increase the response rate. While digitally distributed questionnaires tend to have a lower response rate, an accompanying email and friendly reminders showed to result in an acceptable response rate of 72.9%.

Cross-sectional studies are designed to explore changes.<sup>26</sup> and to challenge possible assumptions made by the researcher. Changes through time were not assessed in current analysis. A mixed methods design with additional qualitative interviews could have provided additional insight into healthcare professionals perceptions' of the psychosocial challenges parents with new-borns admitted to the NICU face.

A technical drawback applicable to the current analysis, is that in case a participant forgot to answer one or more items, the Castor system still indicated that the survey was completed. The participant did not receive a notification that they forgot to answer a question, which affected the number of completed surveys. A survey such as Select Survey (SS-net) did have the option to notify the participant that a question had not been answered, and an response was required to progress through the questionnaire. The SS-net system would therefore be a preferred option as opposed Castor for future analyses. Additionally, it appeared that in some of the cases, hospital server firewalls blocked some correspondence from the Castor survey. The researcher therefore had to, send out additional emails to notify CW Dansen 11

participants to check their spam folder. This might have resulted in a delay in retrieving results, and potentially the loss of some data when participants did not retrieve or read the additional correspondence.

The COVID pandemic may have affected the recruitment yield while managers had to determine whether their personnel could be burdened with additional work by filling in a questionnaire for the purposes of research. Visiting restrictions prohibited an oral explanation of the survey. It is likely that some extent of selection bias seems to have played a role among participating healthcare professionals, as the mean age is approximately 44 years. No particular reasons are known to the researcher why healthcare professionals in this age group were more likely to be invited to participate in the study by their managers.

Since the few missed answers were dichotomised by the researcher as zero, the interpretation of results may therefore be an underestimation.

## **Implications for Clinical Practice and Future Research**

A fast screening tool may aid in identification of gaps in the needs and current psycho-social parental support in NICU wards in the Netherlands. The NICU healthcare professionals can optimise a relationship into a 'triadic' relationship (i.e., infant–parent–staff) by capturing parental needs at an early stage. Additional qualitative research is needed to investigate, and provide meaningful understanding of parental needs. and the healthcare professionals perspective in their role in this triadic relationship.

#### Conclusion

The DT-P was validated on relevance and comprehensiveness by healthcare professionals from Dutch NICU wards. This study showed that overall the DT-P is regarded as a valid and comprehensive tool for quick assessment of potential psychosocial problems in parents with children admitted to the NICU. Additional qualitative research is needed to capture NICU's healthcare professionals perspectives towards this fast screening instrument more profoundly.

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## **TABLES**

Table 1. The definition and formula of I-CVI and S-CVI/Ave

Type of CVI	Definition	Formula
I-CVI (item-level content validity index)	The proportion of content experts giving item a relevance rating of 3 or 4	I-CVI = (agreed item)/ (number of expert)
S-CVI/Ave (scale-level content validity index based on the average method)	The average of the I-CVI scores for all items on the scale or the average of	S-CVI/Ave = (sum of I-CVI scores)/(number of item)
	proportion relevance judged by all experts. The proportion relevant is the average of relevance rating by individual expert.	S-CVI/Ave = (sum of proportion relevance rating)/ (number of expert)

Table 2 Baseline characteristics Healthcare professionals

Characteristics		
Age in years, mean ± SD	43.8 ± 11	
Gender. n(%)	Female 40(78%)	
	Male 11(21%)	
Country of origin	Netherlands 48 (94%)	
	Belgium 2 (4%)	
	Spain 1 (2%)	
Nationality n (%)	Netherlands 49 (96%)	
	Belgium 1 (2%)	
	Spain 1 (2%)	
Profession n (%)(1tm11)	NICU nurse	17(33.3%)
	Neonatologist	7 (13.7%)
	Paediatrician in training	3 (5.9%)
	Social worker	5 (9.8%)
	Physician assistant	5 (9.8%)
	Remedial educationalist	2 (3.9%)
	Pastoral assistant 1 (2%)	
	Speech therapist	1 (2%)
	Psychologist	3 (5.9%)
	Physiotherapist 3 (5.9%)	
	Other	4 (7.8%)
Years of service. mean±SD	16.5 ± 11.9	

Table 3 I-CVI; Cut-off point: >0.78 on relevance and comprehensiveness

Domain: Practical Problems	Relevance I-CVI	Comprehensiveness I-CVI
Q1 Ervaart u praktische problemen ten aanzien van wonen/ huisvesting?	0.80	0.88
Q2 Ervaart u praktische problemen ten aanzien van werk/studie?	0.88	0.82
Q3 Ervaart u praktische financiële/ verzekerings problemen?	0.86	0.84
Q4 Ervaart u praktische problemen met uw huishouden momenteel?	0.61	0.50
Q5 Ervaart u praktische vervoersproblemen?	0.86	0.92
Q6 Ervaart u praktische problemen ten aanzien van de zorg voor de kinderen thuis?	0.94	0.86
Q7 Ervaart u praktische problemen ten aanzien van vrije tijdsbesteding/ ontspanning?	0.65	0.72
Domain: Social problems		
Q8 Ervaart u sociale problemen in omgang met uw (ex) partner?	0.86	0.68
Q9 Ervaart u sociale problemen in omgang met uw kinderen thuis?	0.84	0.66
Q10 Ervaart u sociale problemen in omgang met uw familie?	0.78	0.72
Q11 Ervaart u sociale problemen in omgang met uw vrienden?	0.59	0.74
Domain: Emotional problems		
Q12 Heeft u grip op uw emoties?	0.92	0.64
Q13 Heeft u zelfvertrouwen?	0.82	0.66
Q14 Heeft u last angsten?	0.96	0.70
Q15 Heeft u last van stemmingen?	0.82	0.52
Q16 Ervaart u spanningen?	0.92	0.72
Q17 Ervaart u eenzaamheid?	0.75	0.78
Q18 Ervaart u schuldgevoel?	0.96	0.72
Q19 Ervaart u terugkerende gedachten over bepaalde gebeurtenis(sen)?	0.92	0.72
Q20 Ervaart u problemen met middelen gebruik (bv alcohol, durgs en/of medicatie)?	0.84	0.86
Domain: Physical problems		
Q21 Ervaart u lichamelijke problemen ten aanzien van eten?	0.75	0.84
Q22 Ervaart u lichamelijke problemen ten aanzien van verandering in uw gewicht?	0.73	0.82
Q23 Ervaart u lichamelijke problemen ten aanzien van slapen?	0.39	0.60

Q24 Ervaart u lichamelijke problemen ten aanzien van moeheid?	0.29	0.70
Q25 Ervaart u lichamelijke problemen ten aanzien van uw conditie?	0.90	0.82
Q26 Ervaart u lichamelijke problemen ten aanzien van pijn?	0.84	0.78
Q27 Ervaart u lichamelijke problemen ten aanzien van seksualiteit?	0.47	0.74
Domain: Cognitive problems		
Q28 Ervaart u concentratie problemen?	0.71	0.62
Q29 Heeft u last van vergeetachtigheid?	0.43	0.82
Domain: Education after discharge from hospital		
Q30 Maakt u zich zorgen over het contact met uw kind?	0.94	0.82
Q31 Maakt u zich zorgen over de verzorging van uw kind?	0.94	0.84
Q32 Maakt u zich zorgen over de ontwikkeling van uw kind?	0.96	0.92
Q33 Maakt u zich zorgen over het opvolgen van adviezen/ behandeling/ medicatie?	0.90	0.74
Q34 Maakt u zich zorgen over het slapen van uw kind?	0.82	0.78
Q35 Maakt u zich zorgen over het gedrag/ huilen van uw kind?	0.86	0.80
Domain: Support from environment		
Q36 Ontvangt u voldoende steun uit uw omgeving?	0.96	0.88
Q37 Is dit praktische ondersteuning?	0.92	0.86
Q38 Is dit emotionele ondersteuning?	0.92	0.90
Q39 Ervaart u onbegrip uit uw omgeving?	0.90	0.84
Domain: Others		
Q40 Heeft u zelf een (chronische) ziekte?	0.73	0.84
Q41 Hoe was uw omgang met het medisch personeel tijdens opname?	0.88	0.78
Q42 Wenst u met een deskundige te praten?	0.96	0.76

Original questionnaire in Dutch

I-CVI= Item Content Validity Index

Valued depicted in Orange represent values < 0.78

Table 4 Mean I-CVI's on the specific domains

I-CVI	Relevance	Comprehensiveness
Practical problems	0.80	0.79
Social problems	0.77	0.70
Emotional problems	0.88	0.70
Cognitive problems	0.74	0.83
Physical problems	0.58	0.73
Upbringing after discharge	0.91	0.82
Support from the environment	0.92	0.87
Others	0.86	0.79
S-CVI/Ave(% I-CVI / Experts)	0.81	0.77
S-CVI/Ave (sum of I- CVI / Items)	0.79	0.77

Red rating< 0.60. Green rating > 0.78