

2023-01-06

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Weis, J

<http://hdl.handle.net/10026.1/20148>

10.1111/apa.16661

Acta Paediatrica: Nurturing the Child

Wiley

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Psychometric testing of a Danish version of the Empowerment of Parents in the Intensive Care – Neonatology questionnaire has confirmed validity

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Journal: **Acta Paediatrica**

Acceptance date: **5 January 2023**

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Abstract

Aim: Investigating parent satisfaction with care is important to guide quality development. In this study we translated and validated a Danish version of the empowerment of parents in the intensive care – neonatology (EMPATHIC-N) questionnaire to determine validity in Danish contexts.

Method: A psychometric study design was applied. Translation was performed according to recommended international standards. Confirmatory factor analyses including standardized factor loadings, Cronbach's α reliability estimates, congruent validity, and nondifferential validity testing were applied. The study was performed from June 2017 through November 2019 at a 33-bed level IV neonatal intensive care unit.

Results: Participants were 311 parents (response rate = 42,8%). Confirmative factor analyses disclosed a moderate model fit of the instrument with Comparative Fit Index (CFI) values of 0.83 to 0.92. Cronbach's α showed good reliability (0.82 to 0.93). Congruent validity showed good positive correlations (0.48 to 0.71) between the instrument domains and four overall satisfaction indicators. In search of improved model fit, a version including 27 items was tested. This version showed a better model fit with CFI values of 0.92 to 0.99 and satisfactory Cronbach's α values.

Conclusions: Model fit for the Danish full EMPATHIC-N was moderate. The shorter version showed better psychometric properties.

Keywords: Family-centred care, instrument validation, parent satisfaction questionnaire, preterm infant, quality of healthcare

Key Notes

- The present study validated a Danish version of the Empowerment of Parents in The Intensive Care – Neonatal questionnaire to assess parent satisfaction
- The questionnaire showed overall satisfactory reliability but the model fit was moderate
- Testing a shorter version comprising 27 items showed better psychometric properties; when measuring quality of care, we recommend using this shorter version to reduce the burden on the parents and possibly also contribute to higher response rates

Introduction

Quality of healthcare is prioritised in national and international health policy.¹ Systematic measurement of patient- and family perspectives is central to advancing the quality of care and guide development of healthcare services.^{2,3}

In the neonatal intensive care unit (NICU), exploring the perspectives of parents is particularly important because they are communicating on behalf of their infant as well as themselves. Parents play an essential role in supporting their infants, also during acute illness.^{4,5} However, being parents of a newborn infant in the NICU is often stressful due to concern for the infant, technological equipment, noise, alarms, dependency on collaboration with healthcare professionals, and experiencing a parental role quite different from the expected.⁶ The consequences of their stress may affect the family's life after discharge. Parents are at an increased risk of developing post-traumatic stress disorder or postpartum depression, which may negatively impact parent–infant relationships and the infants' subsequent development.^{7,8}

Family-centred care is an approach that is widely acknowledged as central to delivering high-quality care in the NICU.^{9,10} Research supports that care and treatment according to family-centred care meet the needs of parents and reduce stressors.⁶ The Institute for Patient and Family-Centred Care describes the four core principles dignity and respect, information sharing, participation, and collaboration.¹¹ Dignity and respect emphasise the importance of healthcare professionals listening to the patient and family, and respecting their values, beliefs and cultural backgrounds. Information sharing includes the need for tailored communication and continuous accurate information for the family to participate in care and decision-making. Participation refers to patients and families being supported to participate in care and decision-making at the level they choose. Collaboration underlines the importance of contribution of patients and families to policy and healthcare evaluation, and development beyond their personal meetings with the healthcare system.¹¹ Parent-delivered interventions based on a family-centred care approach can improve infant and parent outcomes. These outcomes include parent well-being and adaptation to the parental role, infant feeding and growth, and length of stay.⁴ Hence, a questionnaire that specifically addresses the needs of NICU parents is required to systematically measure parent satisfaction with care. It is central that parental satisfaction questionnaires are grounded in the family-centred care principles as family-centred care is of great importance to parent outcome. Parent satisfaction as an indicator of quality is important to guide development of NICU care and to ensure quality of care.²

The empowerment of parents in the intensive care-neonatology (EMPATHIC-N)¹² questionnaire was chosen because this questionnaire is thoroughly validated, and is based on the family-centred care principles. In their systematic review of parent satisfaction in NICU questionnaires, Dall'Oglio et al.

identified only two validated instruments that included all family-centred care principles. They considered these two questionnaires suitable for assessing parent satisfaction in NICU as well as representing outcome indicators for future research.¹³ They concluded that the EMPATHIC-N appeared to be the ideal questionnaire based on validity rigor and the number of items. Several translated and validated versions of the Empathic-N are available.¹⁴⁻¹⁸ However, it has not yet been adapted and validated in a Danish context. Validation through psychometric evaluation is required after translation and cultural adaptation to assess the properties of a questionnaire in a new context as language is profoundly influenced by culture.^{19,20} Adapting standardised questionnaires rather than developing new questionnaires allows comparison of results from culturally diverse populations contributing to the existing research on parent satisfaction in NICU. Therefore, the aim of this study was to translate and validate a Danish version of the EMPATHIC-N to determine if the questionnaire is valid for assessing parent satisfaction in a Danish context.

Patients and methods

A psychometric study design was applied to evaluate the validity of a Danish version of the EMPATHIC-N questionnaire. The original Dutch questionnaire was translated and culturally adapted to a Danish setting according to international standards for translation and cultural adaptation of patient reported outcome measures.^{19,20} The results were reported according to an international guideline for selection of health measurement instruments.²¹

Setting

The study was performed at a level IV NICU at Copenhagen University Hospital Rigshospitalet containing 33 beds with around 1200 infants admitted annually. Admissions include premature infants from 23 weeks gestational age, newborn infants with congenital diseases including all surgery, with organ dysfunction including extra corporal membrane oxygenation, with birth-related complications, infections, or other issues, and for children up to one year of age admitted in need of ventilator treatment. Infants were cared for in double occupancy rooms with a bed for one parent beside the infants' incubator. During the study period, there were no changes in the categories or numbers of patients cared for in the unit, environments, or care and treatment strategies.

Sample

We invited 727 parents of preterm or sick newborn infants admitted to the NICU for at least 48 hours to participate in the study. Parents had to be able to read Danish to answer the questionnaire. Parents of multiple births received only one questionnaire. Parents of infants who died in the unit were excluded as, according to unit practice, these families were invited to a conversation reviewing care and treatment six weeks after the death of their infant. The targeted sample size was 250

participants as this was close to the number of participants in the original Dutch study. This would also be suitable for performing psychometric testing. Data were collected from June 2017 to the end of November 2019.

Instrument

The EMPATHIC-N questionnaire was developed in the Netherlands.¹² The items were generated based on parent and NICU staff perspectives,²² as well as the content of existing satisfaction questionnaires.¹² The EMPATHIC-N consists of 57 items exploring parents' experiences within five domains: information (12 items); care and treatment (17 items); organisation (eight items); parental participation (eight items); and professional attitude (12 items).¹² Items are rated on a six-point scale from one matching certainly no to six matching certainly yes or the alternative not applicable (N/A). Four questions reflecting overall satisfaction with care are included. Two of these have the same rating scale as the satisfaction items, and two questions concerning overall satisfaction with the performances of physicians and nurses are rated on a 10 point scale ranging from one very poor to 10 excellent. Five open questions provide parents the opportunity to elaborate on their experiences of the performances of physicians and nurses, admission to the unit, the time during admission, transfer or discharge, and general experiences. In addition, the first part of the questionnaire contains three general questions about who answers the questionnaire, cultural background, and level of education. The original EMPATHIC-N questionnaire showed adequate reliability estimates with Cronbach's α values on domain levels between 0.82 and 0.95.¹²

Translation and cultural adaption of EMPATHIC-N

Permission to translate and culturally adapt the EMPATHIC-N to Danish context was obtained from the owner of the original questionnaire (JML). The translation process was performed in accordance with the framework presented by Wild et al.²⁰ Initially, the Dutch version was translated into Danish independently by three people holding the required competencies. These comprised Danish native tongue, fluent in Dutch, and experience with medical translation.²⁰ The three translations were discussed at a consensus meeting between translators and the project manager to obtain agreement on a version for back-translation. A few conceptual issues were clarified with the owner of the original questionnaire. To ensure understanding of the wording by the target group, feedback from two parent couples was obtained. The agreed consensus version was back translated into Dutch by a professional native Dutch speaking translator. A final version with few modifications was agreed at a consensus meeting between the project manager, a Dutch-Danish translator, and the professional Danish-Dutch translator. The Danish version was named Empowerment of parents in the intensive care-neonatology-Denmark (EMPATHIC-N-DK) (*Appendix 1A*).²³

Data collection

The EMPATHIC-N-DK was set up in a secure database using an Analyzer survey application (Analyzer Software A/S, Copenhagen, Denmark). The survey was distributed electronically with interface adapted for response on computer, tablet, or smartphone.

During admission, parents signed a statement and provided their e-mail address if they agreed to being contacted after discharge to give their feedback on experiences of the admission. Two weeks after discharge, e-mails were sent to one of the parents containing information about the study and a link to the on-line questionnaire. The information clarified for the parents that answering the questionnaire was considered to be their consent to participate in the study. Furthermore, this was their consent to data being collected from the infants' medical records including gestational age, diagnosis, birthweight, length of admission, need of ventilator treatment, and need of continuous positive airway pressure (CPAP) treatment. The parents were encouraged to contact the project manager if they wanted verbal information or had any questions. Contact information for the research team was provided in the information material and in the introductory text of the questionnaire. In cases of no response, e-mails were sent again two weeks after the first e-mail repeating the invitation.

The parents' e-mail addresses were connected to an internal identification number for the infant in a secure log. This made it possible to identify the relevant medical records, if parents consented to data collection by answering the questionnaire. Anonymized data from the infants' medical records mentioned above were entered into the secure Analyzer database by one designated unit secretary.

Statistical analyses

A psychometric evaluation of EMPATHIC-N-DK was performed. We applied the same statistical analyses which were used in the psychometric evaluation of the original Dutch EMPATHIC-N.¹² The testing was conducted through sequential procedures: confirmatory factor analyses, reliability, and validity. Confirmatory factor analysis models were fitted for each of the five domains to obtain performance statistics including comparative fit index (CFI; preferably ≥ 0.95), the Tucker-Lewis Index (preferably ≥ 0.95), the root mean square error of approximation (preferably < 0.06) and the standardized root mean squared residual (SRMR; preferably < 0.08). Means, standard deviations, and standardized factor loadings derived from the models were presented for each item within the five domains. The loadings represent the correlations between the observed item scores and the unobserved domain. Furthermore, Cronbach's α reliability estimates were calculated to present how closely the items within a domain were related. Values ≥ 0.70 were considered satisfactory Cronbach's α on domain level. Validity refers to the degree in which the instrument measures what it is intended to measure. Congruent validity was assessed by computing the Spearman rank correlation matrix between the domain means and the four general satisfaction indicator questions.

Finally, nondifferential validity was tested by comparing the domain means between levels of four binary variables comprising: mechanical ventilation; length of stay \geq seven days; gestational age $<$ 30 weeks; and non-Danish culture. For this purpose, values of Cohen's d with 95% confidence intervals will be presented. The effect size is small with a value of 0.20, medium with 0.50, and large with $>$ 0.80.

Data management and analyses were conducted using Stata/MP 14.2 (StataCorp LLC, Texas, USA). The confirmatory factor analyses were performed using the structural equation modelling framework.

Ethical considerations

Approval to collect, store and analyse data was obtained from the Knowledge Centre on Data Protection Compliance agreement number 8002X000005krwM. They also approved parents giving consent to participate by answering the questionnaire because of the detailed written information with the possibility to contact the project manager. Ethical approval was not applied for as this is not required for this type of study according to Danish legislation.²⁴ Parents were assured confidentiality, concealment of identity and anonymisation of data in data management and publication of results.

Results

We invited 727 parents to participate, and 316 questionnaires were responded. Five respondents were excluded as they did not fulfill the inclusion criteria of at least 48 hours stay in the unit. In total, 311 responses were included in analyses corresponding to a response rate of 42,8%. Data on 324 infants were included because 13 twins participated. In 69% of cases, the questionnaire was answered on a smartphone, and the second choice of device was a computer (26%). Mothers most frequently completed the questionnaire (60%), followed by both parents together (29%). Characteristics of parents and infants are presented in Table 1.

Overall, our results reflected high parent satisfaction (Table 2) with mean domain scores ranging from 4.98 (SD 0.87) to 5.29 (SD 0.83) of a maximum of 6.0. Mean values for all items were high (Table 3), with only one mean value below 4 being The neonatology unit made us feel safe (M 3.97, SD 1.81).

Cronbach's α of the five domains showed good reliability ranging from 0.82 to 0.93 (Table 2). The Confirmative factor analyses disclosed a moderate model fit of the 57 items within the five domains with CFI and Tucker-Lewis Index both below 0.95, but adequate SRMR values ranging from 0.04 to 0.07 (Table 3).

Apart from three items, standardized factor loadings were adequate, with values between 0.42 and 0.88 (Table 4). Congruent validity showed good positive correlations from 0.48 to 0.71 between the five domains and the four overall satisfaction indicator questions (Table 5). Nondifferential validity assessed by calculating the standardized mean difference, Cohen's *d*, between the five domains and four population variables (Table 6) showed very small effect sizes except between Organisation and Length of stay \geq seven days (Cohen's *d* -0.32, 95% CI -0.54;-0.09), and between Gestational age < 30 weeks and Care and treatment (Cohen's *d* 0.42, 95%CI 0.12;0.73), Organisation (Cohen's *d* 0.54, 95%CI 0.28;0.90), and Professional attitude(Cohen's *d* 0.48, 95%CI 0.17;0.78). In five items, the N/A response rate was above 25%, with N/A responses between 89 and 224. The item having 224 N/A responses was the item Our cultural background was taken into account, where 217 of 294 respondents with Danish culture (74%) and seven of 17 respondents with non-Danish culture (41%) responded N/A.

To test whether a shorter version would provide improved model fit, a short version with 27 items from the original EMPATHIC-N was tested, comprising: Information four items; Care and treatment six items; Parental participation six items; Organisation five items; and Professional attitude six items (*marked with grey in table 4*). The 27 items out of the 57 translated items were chosen guided by items in the validated EMPATHIC-NICU-USA Questionnaire,¹⁶ which is a modified version of EMPATHIC-30²⁵ largely overlapping with EMPATHIC-N items. The analyses described above were reproduced for this shorter version. Three of the five items with a high N/A response rate were left out when shortening the questionnaire. The questions The unit could easily be reached by telephone and Our cultural background was taken into account were retained as these are part of the EMPATHIC-NICU-USA.¹⁶ The 27-item version showed a better model fit within the five domains with CFI values of 0.92 to 0.99 and SRMR of 0.03 to 0.05 (Table 7). Cronbach's α values were lower but still satisfactory ranging from 0.73 to 0.88. Congruent validity remained good, and nondifferential validity were largely unchanged.

Discussion

The purpose of this study was to translate and investigate the validity and reliability of the EMPATHIC-N-DK assessed in a Danish sample of 311 NICU parents. We tested the full 57-item version as well as a 27-item version. Both versions showed good reliability with satisfactory Cronbach's α values. The confirmatory factor analysis indicated that a shortened 27-item version had a better statistical fit compared to the 57-item version. Therefore, it could be advantageous to use the shortened version. Shorter versions of the EMPATHIC-N have been tested in NICUs in other

countries with good results.^{16,18} Using a shorter version may ease the response-burden on the parents^{16,25} and this may help improve the response rate.

Overall, our results showed that parent satisfaction was high with mean domain scores around five and all mean item scores above four except for the item The neonatology unit made us feel safe (mean 3.97, SD 1.81). This item needs to be investigated further as this is a low item value. The original as well as other translated versions all show mean item-values for this item above four.^{12,14,16,18} This low value might reflect that the parents' understanding of the question deviates from the intended meaning. They may think that experiencing life with a very small or very sick infant does not make you feel safe. Still, the parents should experience safety in care and treatment. This item has been excluded in the 27-item version. If using the 57-item version, the wording of this item should be investigated further for instance by discussing the understanding of the question with some parents.

When we reduced the questionnaire to the 27-item version, we considered excluding the five items with an N/A response rate above 25%. However, we retained the item Our cultural background was taken into account. We perceive this item as being highly expressive of the family-centred care approach, one of the basic principles of family-centred care being respecting values, beliefs, and cultural background.¹¹ The high N/A response rate in this study could reflect the small number of non-Danish participants in this sample. In other hospital settings in Denmark, the proportion of parents with a non-Danish background may be higher than in this highly specialized NICU in the capital of Denmark. Hence, the item may receive higher response rates in other settings. We also retained the item The unit could easily be reached by telephone as we find it important that the unit is easy to contact. The high N/A response rate may reflect that one parent or both were always admitted with the infant. The parents probably contacted each other rather than contacting the hospital when not in the unit. In addition, retaining these items increases comparability with results from other countries as the shorter versions used in other NICUs are based on the EMPATHIC-30 where these items are included.

Survey responses mirror a balance between expectations to care and experiences of care. Culture, patient outcome, earlier experiences with and expectations to healthcare services are factors that influence responders' answers.^{26,27} Questionnaires inherently do not catch nuances and depth of the parents' often vulnerable situation and their individual experiences. It can be questioned whether it is possible to measure such a complicated and composite concept as parent satisfaction with neonatal care with a questionnaire. The EMPATHIC-N is thoroughly developed based on family-centred care principles and information from existing questionnaires as well as perspectives of key stakeholders, NICU staff, and parents.¹² A large number of items were ranged by

148 parents contributing to ensuring that all included items covered important areas¹² which indicates that the right questions are included.²⁶ The inclusion of open-ended questions exploring parents' views of what was good and what could be improved is also a strength of the questionnaire. The results of these questions are not included in this study. Although parents in general may be satisfied with care resulting in some ceiling effect of the questionnaire, areas for improvement may be identified through parents' spontaneous responses to the open-ended questions.²⁸ Such feedback may contribute to improving quality of care according to family-centred care principles. In this way the family-centred care principle of collaboration, where patients and families contribute to policy and healthcare evaluation and development beyond their personal meetings with the healthcare system, may also be fulfilled.¹¹

Measuring parent satisfaction may both be used to monitor quality development processes in clinical practice and as research outcome. When using a questionnaire for quality evaluation or research, it is important that this is not the initial investigation of the area. For some years, qualitative research has been used to investigate parents' experiences of NICU admission.²⁹ It is therefore relevant to use questionnaires representing a quantitative approach when the aim is to obtain knowledge on parents' satisfaction general, to assess results of new interventions, as well as to identify possible quality problems. We suggest using the 27-item version in clinical practice as well as in research due to the reduced burden on the parents in addition to better model fit. Measuring parent satisfaction remains a relevant quality indicator when using a validated instrument with the option to benchmark practices with other NICUs in Denmark and beyond.

There were some limitations to our study. Only one hospital participated in the study. However, we do not assume that the validity of the questionnaire would be much different if we had included more hospitals, since Denmark is a small and relatively homogeneous country and the NICUs are situated in the four major cities in the country. The results of the validity testing after transferring the instrument into a Danish context did not differ much from the results of the original Dutch study. We only achieved a response rate of 42,8%, which may have resulted in selection bias, and reduced the external validity of the results.³⁰ For instance, the majority of the parents had at least 3 years of secondary education (75% of the mothers and almost 60% of the fathers). Apart from this socioeconomic bias it is also likely that those with stronger opinions were overrepresented. However, we do not consider this to be a major problem in the context of testing questionnaire validity. Unfortunately, we have no data on the non-responders. There may be several reasons for the low response rate including the way of administration, the fact that the participants were invited to participate in a study rather than in routine use of satisfaction questionnaires, and the length of the questionnaire. Furthermore, the timing of the distribution may have contributed because some

families might still be admitted to local neonatal units or struggling with establishing their family lives after discharge. We chose electronic distribution of the questionnaire because most mail is sent electronically today in Denmark. We assumed that having more options for responding by using smartphone, tablet, or computer as desired would make it easy to respond for the parents. Even though electronic communication is well established in Denmark, using a hybrid delivery method combining regular mail invitation, and questionnaire with an e-mail containing a link to an electronic questionnaire could improve response rates preserving the advantage of the digital data entry.³¹ Other strategies for improving response rates are shorter questionnaires, the appearance of the questionnaire, and sending up to three reminders.^{32,33} For future use, the questionnaire may benefit from being reduced to the 27 items. It could be an option to split some of the items referring to doctors and nurses in the same item into two individual items as seen in EMPATHIC-30.

Only one parent in a couple received an e-mail, and mostly the mother received the e-mail. The rationale for this was that the mother was most likely to be at home being able to find time for responding. However, this may be a flawed assumption as the mothers often are challenged finding a rhythm with the new baby and balancing family life, including paying attention to possible siblings. In the future, both parents should have the opportunity to respond individually. Parents in a couple are likely to disagree on at least some of the items and should have the possibility of responding on their own, and fathers may have views that differ systematically from mothers. Providing both parents with the opportunity to give their feedback may also improve family response rates including perspectives of more families. Some families were transferred to local hospitals for the last part of the admission when the infant was stable. Thus, more families may still have been challenged by hospitalization when they received the questionnaire and therefore had no surplus to respond. Even though it is recommended in the original paper to wait a couple of weeks before sending the questionnaire, it could be considered to ask the parents to respond during the last 24 hours they are in the unit. This approach has been used in other settings and may lead to higher response rates.^{16,17} Lastly, there were only a few non-Danish participants. In this study we evaluated the properties of the Danish version of the EMPATHIC-N. But in the future, versions in other languages may be needed to evaluate the quality of care in a NICU, including perspectives of non-Danish parents.

Conclusion

Parents of NICU infants have unique knowledge, experiences, and needs, and including these perspectives in treatment and care are crucial to ensure high quality and value for the families. The EMPATHIC-N-DK comprising 57 items was a valid questionnaire performing acceptably in the psychometric evaluation. However, evaluation of the shorter version, the EMPATHIC-N-DK-27,

showed better psychometric properties. This shorter version may be a good choice for evaluating parent satisfaction in Danish NICUs as this also could be an advantage to reduce the burden on the parents as well as achieving higher response rates. Distribution by e-mail alone may not be sufficient to obtain acceptable response rates. Thus sending information by regular mail in combination with an e-mail with a link to a digital response is recommended to preserve the advantage of digital data entry.

Acknowledgements

We would like to thank all the parents for taking their time to participate in this study. Furthermore, we would like to thank secretary Lisbeth Sloth Lemvigh Castaldo for helping with distribution of the questionnaire and data collection.

Funding

This research received no specific funding

Conflict of interest

The authors have no conflict of interest to declare

Abbreviations: EMPATHIC-N, empowerment of parents in the intensive care-neonatology; NICU, neonatal intensive care unit; CFI, comparative fit index, CFI; SRME, standardized root mean squared residual; SD, standard deviation; CI, confidence interval; N/A, not applicable;

Data Accessibility Statement

Data cannot be shared publicly because of legal and ethical restrictions on sharing deidentified data. Data are available upon request from corresponding author.

References

1. Busse R PD, Quentin W. An introduction to healthcare quality: defining and explaining its role in health systems. In: Busse R KN, Panteli D et al, ed. *Improving healthcare quality in Europe: Characteristics, effectiveness and implementation of different strategies* Copenhagen (Denmark): European Observatory on Health Systems and Policies; 2019. *Health Policy Series*.
2. Nickel WK, Weinberger SE, Guze PA. Principles for Patient and Family Partnership in Care: An American College of Physicians Position Paper. *Ann Intern Med*. Dec 4 2018;169(11):796-799. doi:10.7326/m18-0018
3. VIBIS. Videnscenter for brugerinddragelse i sundhedsvæsenet / Knowledge center for user involvement in healthcare Accessed 14 December 2021, 2021. <https://danskepatienter.dk/vibis/om-brugerinddragelse>
4. Franck LS, O'Brien K. The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. *Birth Defects Res*. Sep 1 2019;111(15):1044-1059. doi:10.1002/bdr2.1521
5. Gómez-Cantarino S, García-Valdivieso I, Moncunill-Martínez E, et al. Developing a Family-Centered Care Model in the Neonatal Intensive Care Unit (NICU): A New Vision to Manage Healthcare. *Int J Environ Res Public Health*. Oct 1 2020;17(19)doi:10.3390/ijerph17197197
6. Govindaswamy P, Laing S, Waters D, et al. Needs and stressors of parents of term and near-term infants in the NICU: A systematic review with best practice guidelines. *Early Hum Dev*. Dec 2019;139:104839. doi:10.1016/j.earlhumdev.2019.104839
7. Feeley N, Zerkowitz P, Cormier C, et al. Posttraumatic stress among mothers of very low birthweight infants at 6 months after discharge from the neonatal intensive care unit. *Appl Nurs Res*. May 2011;24(2):114-7. doi:10.1016/j.apnr.2009.04.004
8. Schechter R, Pham T, Hua A, et al. Prevalence and Longevity of PTSD Symptoms Among Parents of NICU Infants Analyzed Across Gestational Age Categories. *Clin Pediatr (Phila)*. Feb 2020;59(2):163-169. doi:10.1177/0009922819892046
9. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. *Critical care medicine*. Jan 2017;45(1):103-128. doi:10.1097/ccm.0000000000002169
10. Gooding JS, Cooper LG, Blaine AI, et al. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Semin Perinatol*. Feb 2011;35(1):20-8. doi:10.1053/j.semperi.2010.10.004
11. Institute for Patient and Family Centered Care. Accessed 14 Juni 2022. <https://www.ipfcc.org/about/pfcc.html>

12. Latour JM, Duivenvoorden HJ, Hazelzet JA, et al. Development and validation of a neonatal intensive care parent satisfaction instrument. *Pediatr Crit Care Med*. Sep 2012;13(5):554-9. doi:10.1097/PCC.0b013e318238b80a
13. Dall'Oglio I, Mascolo R, Gawronski O, et al. A systematic review of instruments for assessing parent satisfaction with family-centred care in neonatal intensive care units. *Acta Paediatr*. Mar 2018;107(3):391-402. doi:10.1111/apa.14186
14. Dall'Oglio I, Fiori M, Tiozzo E, et al. Neonatal intensive care parent satisfaction: a multicenter study translating and validating the Italian EMPATHIC-N questionnaire. *Ital J Pediatr*. Jan 5 2018;44(1):5. doi:10.1186/s13052-017-0439-8
15. Gomez DB, Vidal SA, Lima LC. Brazilian adaptation and validation of the Empowerment of Parents in the Intensive Care-Neonatology (EMPATHIC-N) questionnaire. *J Pediatr (Rio J)*. Mar-Apr 2017;93(2):156-164. doi:10.1016/j.jpmed.2016.06.007
16. Lake ET, Smith JG, Staiger DO, et al. Measuring Parent Satisfaction With Care in Neonatal Intensive Care Units: The EMPATHIC-NICU-USA Questionnaire. *Front Pediatr*. 2020;8:541573. doi:10.3389/fped.2020.541573
17. Papamichael E, Ioannou M, M AT. EMPATHIC-N in a Greek-Cypriot sample: confirming its factorial structure. *BMC Health Serv Res*. Dec 14 2018;18(1):968. doi:10.1186/s12913-018-3793-3
18. Tiryaki Ö, Zengin H, Çınar N, et al. Turkish Adaptation and Validation of the EMpowerment of PArents in THE Intensive Care (EMPATHIC-30) Questionnaire to Measure Parent Satisfaction in Neonatal Intensive Care Units. *Front Pediatr*. 2020;8:421. doi:10.3389/fped.2020.00421
19. Endacott R, Benbenishty J, Seha M. Preparing research instruments for use with different cultures. *Intensive Crit Care Nurs*. Apr 2010;26(2):64-8. doi:10.1016/j.iccn.2009.12.005
20. Wild D, Grove A, Martin M, et al. Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value Health*. Mar-Apr 2005;8(2):94-104. doi:10.1111/j.1524-4733.2005.04054.x
21. Gagnier JJ, Lai J, Mokkink LB, et al. COSMIN reporting guideline for studies on measurement properties of patient-reported outcome measures. *Qual Life Res*. Apr 5 2021;doi:10.1007/s11136-021-02822-4
22. Latour JM, Hazelzet JA, Duivenvoorden HJ, et al. Perceptions of parents, nurses, and physicians on neonatal intensive care practices. *J Pediatr*. Aug 2010;157(2):215-220.e3. doi:10.1016/j.jpeds.2010.02.009
23. Beck SA. Forældres tilfredshed med familiecentreret pleje på neonatalafdelingen - ved anvendelse af spørgeskema oversat og valideret til danske forhold (Parent satisfaction with family-centred Care in the NICU - by application of a questionnaire translated and validated to Danish context). Master's thesis. *Master's Thesis*. 2014:1-106.

24. National videnskabsetisk komité NEC. Hvad skal jeg anmelde - What should I report. Accessed 13. december 2021. <https://www.nvk.dk/forsker/naar-du-anmelder/hvilke-projekter-skal-jeg-anmelde>
25. Latour JM, Duivenvoorden HJ, Tibboel D, et al. The shortened EMpowerment of PARENTS in THE Intensive Care 30 questionnaire adequately measured parent satisfaction in pediatric intensive care units. *J Clin Epidemiol*. Sep 2013;66(9):1045-50. doi:10.1016/j.jclinepi.2013.02.010
26. Michelson KN. A new satisfaction tool: what do we do with it? *Pediatr Crit Care Med*. Sep 2012;13(5):601-2. doi:10.1097/PCC.0b013e31824557b4
27. Bjertnaes OA, Sjetne IS, Iversen HH. Overall patient satisfaction with hospitals: effects of patient-reported experiences and fulfilment of expectations. *BMJ Qual Saf*. Jan 2012;21(1):39-46. doi:10.1136/bmjqs-2011-000137
28. Terp K, Weis J, Lundqvist P. Parents' Views of Family-Centered Care at a Pediatric Intensive Care Unit-A Qualitative Study. *Front Pediatr*. 2021;9:725040. doi:10.3389/fped.2021.725040
29. Brødsgaard A, Pedersen JT, Larsen P, et al. Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis. *J Clin Nurs*. Sep 2019;28(17-18):3117-3139. doi:10.1111/jocn.14920
30. Johnson TP, Wislar JS. Response rates and nonresponse errors in surveys. *Jama*. May 2 2012;307(17):1805-6. doi:10.1001/jama.2012.3532
31. Neve OM, van Benthem PPG, Stiggelbout AM, et al. Response rate of patient reported outcomes: the delivery method matters. *BMC Med Res Methodol*. Oct 22 2021;21(1):220. doi:10.1186/s12874-021-01419-2
32. Edwards PJ, Roberts I, Clarke MJ, et al. Methods to increase response to postal and electronic questionnaires. *Cochrane Database Syst Rev*. Jul 8 2009;(3):Mr000008. doi:10.1002/14651858.MR000008.pub4
33. Zha N, Alabousi M, Katz DS, et al. Factors Affecting Response Rates in Medical Imaging Survey Studies. *Acad Radiol*. Mar 2020;27(3):421-427. doi:10.1016/j.acra.2019.06.005

Table 1. Characteristics of parents and infants

Parent responses (N=311)		
Cultural background (n / %)		
Danish	294 / 94,5%	
Other	17 / 5,5%	
Education level (n / %)		
	Mothers n=309	Fathers n=302
Elementary school or less	7 / 2,2%	14 / 4,5%
High school degree	23 / 7,4%	25 / 8,0%
Occupational education (apprenticeship, traineeship e.g. carpentry, welding)	11 / 3,5%	39 / 12,5%
Short secondary education (2-3 years)	30 / 9,6%	31 / 10,0%
Medium-length secondary education (3-4 years)	96 / 30,9%	61 / 19,6%
Long secondary education (4-6 years or longer)	139 / 44,7%	121 / 38,9%
Not applicable	2 / 0,6%	11 / 3,5%
Infant characteristics (N=324)		
Gender: boy (n / %)	202 / 62,3%	
Gestational age w ^{+d} (mean/min-max)	35 ⁺⁵ / 23 ⁺¹ – 42 ⁺²	
Birth weight g (mean/min-max)	2611 / 470 - 4900	
Length of stay d (mean/min-max)	13 / 2 - 113	
Days on ventilator n=98 (mean/min-max)	6,5 / 1 - 85	
Days on CPAP n=189 (mean/min-max)	9 / 1 - 102	
Diagnosis (n / %)		
Preterm	125 / 38,6%	
Common neonatal complications	144 / 44.4%	
Congenital Cardiac Defect	28 / 8,6%	
Congenital Abdominal Defect	27 / 8,3%	

N=number of; w=weight; d=days; g=grams; in some cases, parent education was not answered (2 mothers and 9 fathers); Common neonatal complications includes respiratory complications, asphyxia, infections, cerebral complications, hypoglycaemia, complicated jaundice, and other conditions.

Table 2. Reliability estimates: domain-specific means, SDs and Cronbach's alpha, full version

Domains (Statements)	Mean	SD	α
Information (12)	5.06	0.90	0.91
Care and treatment (17)	5.21	0.84	0.93
Parental participation (8)	5.29	0.83	0.87
Organisation (8)	4.98	0.87	0.82
Professional attitude (12)	5.24	0.85	0.92

α =Cronbach's α on standardised items; satisfactory value ≥ 0.70

Table 3. Confirmatory factor analyses using the 57 items of the full version

Domains	Items No.	No.	Chi-Square test of model Fit p	Comparative Fit Index	Tucker-Lewis Index	Root Mean Square Error of Approximation	Standardised Root Mean Squared Residual
Information	12	311	< 0.001	0.90	0.88	0.11	0.05
Care and treatment	17	311	< 0.001	0.85	0.82	0.12	0.06
Parental participation	8	311	< 0.001	0.92	0.89	0.12	0.05
Organisation	8	311	< 0.001	0.83	0.76	0.15	0.07
Professional attitude	12	311	< 0.001	0.91	0.89	0.11	0.04

Good model fit: Comparative Fit Index preferably ≥ 0.95 ; Tucker Lewis Index preferably ≥ 0.95 ; Root Mean Square Error of Approximation preferably ≤ 0.06 ; Standardized Root mean Squared Residual preferably ≤ 0.08

Table 4. Means, SDs and standardised factor loadings from the confirmatory factor analyses of the 57 items

	Mean	SD	Standardized Factor Loadings
Information			
The doctors and nurses gave honest information to us	5.41	1.08	0.73
We were always informed right away when our child's physical condition worsened	5.21	1.11	0.81
The information provided by the doctors and nurses was understandable	4.46	1.50	0.68
Our questions were clearly answered	5.26	1.19	0.62
The doctor clearly informed us about the consequences of our child's treatment*	5.10	1.21	0.82
We were given clear information about our child's disease	5.05	1.24	0.76
We received clear information about the examinations and tests	5.30	1.02	0.82
The information brochure we received was complete and clear	4.87	1.26	0.56
We received understandable information about the effects of the drugs	4.52	1.50	0.50
We had daily talks about our child's care and treatment with the doctors and the nurses	4.58	1.56	0.46
The doctor informed us about the expected health outcomes of our child	5.30	1.04	0.66
The information given by the doctors and nurses was always the same	5.42	1.01	0.73
Care & Treatment			
When our child's condition worsened, action was immediately taken by the doctors and nurses	5.29	1.05	0.75
The doctors and nurses are real professionals; they know what they are doing	5.47	0.85	0.56
At admission our child's medical history was known by the doctors and nurses	5.50	0.98	0.72
Our child was always well taken care of by the nurses while in the incubator/bed	5.11	1.27	0.57
During acute situations there was always a nurse to support us	5.14	1.24	0.50
Our child's comfort was taken into account by the doctors and nurses	5.26	1.06	0.62
The team was alert to the prevention and treatment of pain in our child	5.56	0.87	0.61
The correct medication was always given on time	5.39	0.97	0.78
Our child's needs were well taken care of	5.35	1.11	0.82
Attention was paid to our child's developmental by the doctors and nurses	5.50	0.91	0.81
The team had a common goal: the best care and treatment for our child and ourselves	4.32	1.64	0.52
The team was caring to our child and to us	4.92	1.34	0.77
The doctors and nurses worked closely together	4.85	1.40	0.83
Transferral of care from the neonatal intensive care unit staff to colleagues in the high-care unit or pediatric ward had gone well	5.28	1.14	0.85
The doctors and nurses responded well on our own needs	5.22	1.24	0.68
We were emotionally supported	5.50	0.91	0.68
Every day we knew who of the doctors and nurses was responsible for our child	4.78	1.56	0.23
Parental Participation			
We had confidence in the team	5.02	1.26	0.63
Even during intensive procedures we could always stay close to our child	5.39	1.05	0.78
The nurses stimulated us to help in the care of our child	5.44	0.96	0.65
The nurses helped us in the bonding with our child	5.40	0.92	0.43
We were encouraged to stay close to our child	5.60	0.86	0.72
The nurses had trained us the specific aspects of newborn care	5.36	1.09	0.88
We were actively involved in decision-making on care and treatment of our child	5.32	1.07	0.78
Before discharge the care for our child was once more discussed with us	4.75	1.53	0.52
Organization			
The unit could easily be reached by telephone	5.39	1.10	0.81
Our child's incubator or bed was clean	5.68	0.64	0.57
The team worked efficiently	5.52	0.91	0.73
There was a warm atmosphere in the Neonatology unit without hostility	5.36	1.12	0.32
The Neonatology unit made us feel safe	3.67	1.81	0.46
The Neonatology unit was clean	5.06	1.26	0.52
Noise in the unit was muffled as good as possible	4.21	1.70	0.56
There was enough space around our child's incubator/bed	5.19	1.24	0.76
Professional Attitude			
Our cultural background was taken into account	5.11	1.15	0.59
Our child's health always came first for the doctors and nurses	5.32	1.07	0.83
The team worked hygienically	5.68	0.71	0.53
The team showed respect for our child and for us	4.51	1.60	0.56
The team respected the privacy of our child's and of us	5.44	0.99	0.87
There was a pleasant atmosphere among the staff	5.11	1.26	0.58
We felt welcome by the team	5.39	0.95	0.76
The doctors and nurses always took time to listen to us	5.33	1.09	0.88
Despite the workload, sufficient attention was paid to our child and to us by the team	5.16	1.27	0.82
We received sympathy from the doctors and nurses	5.36	1.13	0.38
Nurses and doctors always introduced themselves by name and function	5.42	1.03	0.81
At our bedside, the discussion between the doctors and nurses was only about our child	5.09	1.24	0.85

*items marked with grey are included in a short 27-item version

Table 5. Congruent validity of scales: spearman correlations with four satisfaction indicators, full version

	No.	Suggest Neonatal Intensive Care Unit to others	Come Back Again If Needed	Overall Satisfaction With Physicians	Overall Satisfaction With Nurses
Information	311	0.52	0.52	0.61	0.57
Care and treatment	311	0.60	0.58	0.56	0.71
Parental participation	311	0.54	0.52	0.48	0.59
Organisation	311	0.66	0.64	0.45	0.58
Professional attitude	311	0.68	0.65	0.50	0.71

Table 6. Nondifferential validity: differences between domains and characteristics, full version

	Yes			No			Cohen's <i>d</i>	95% <i>CI</i>
	No.	Mean	SD	No.	Mean	SD		
Mechanical Ventilation								
Information	97	5.10	0.80	214	5.04	0.94	-0.07	(-0.31;0.17)
Care and treatment		5.26	0.80		5.18	0.85	-0.09	(-0.33;0.15)
Parental participation		5.27	0.80		5.29	0.85	0.02	(-0.22;0.26)
Organisation		4.92	0.87		5.01	0.87	0.11	(-0.13;0.35)
Professional attitude		5.21	0.83		5.25	0.87	0.04	(-0.20;0.28)
Length of stay ≥ 7 days								
Information	130	5.01	0.89	181	5.09	0.91	-0.09	(-0.32;0.14)
Care and treatment		5.16	0.86		5.24	0.82	-0.09	(-0.32;0.13)
Parental participation		5.34	0.76		5.25	0.88	0.11	(-0.12;0.33)
Organisation		4.82	0.87		5.09	0.85	-0.32	(-0.54;-0.09)
Professional attitude		5.13	0.88		5.32	0.83	-0.22	(-0.44;0.01)
Gestational age < 30 weeks								
Information	49	4.85	0.97	262	5.10	0.88	0.28	(-0.03;0.58)
Care and treatment		4.91	1.02		5.26	0.79	0.42	(0.12;0.73)
Parental participation		5.17	0.78		5.31	0.84	0.17	(-0.14;0.47)
Organisation		4.56	0.94		5.06	0.83	0.59	(0.28;0.90)
Professional attitude		4.90	0.99		5.30	0.81	0.48	(0.17;0.78)
Non-Danish Culture								
Information	17	4.97	0.73	294	5.07	0.91	-0.11	(-0.60;0.38)
Care and treatment		5.15	0.67		5.21	0.85	-0.08	(-0.56;0.41)
Parental participation		5.24	0.69		5.29	0.84	-0.06	(-0.55;0.43)
Organisation		5.12	0.72		4.97	0.88	0.17	(-0.32;0.66)
Professional attitude		5.16	0.73		5.24	0.86	-0.10	(-0.59;0.39)

Table 7. Confirmatory factor analyses using only the 27 items of the short version

Domains	Items No.	No.	Chi-Square test of model Fit <i>p</i>	Comparative Fit Index	Tucker-Lewis Index	Root Mean Square Error of Approximation	Standardised Root Mean Squared Residual
Information	4	311	0.0018	0.97	0.90	0.13	0.04
Care and treatment	6	311	< 0.001	0.95	0.92	0.09	0.03
Parental participation	6	311	< 0.001	0.96	0.94	0.11	0.04
Organisation	5	311	< 0.001	0.92	0.84	0.16	0.05
Professional attitude	6	311	0.0704	0.99	0.98	0.05	0.03

Good model fit: Comparative Fit Index preferably ≥ 0.95 ; Tucker Lewis Index preferably ≥ 0.95 ; Root Mean Square Error of Approximation preferably ≤ 0.06 ; Standardized Root mean Squared Residual preferably ≤ 0.08

JERES ERFARING TÆLLER



PLADS TIL LOGO

EMPOWERMENT OF **PA**RENTS IN
THE INTENSIVE **CA**RE **N**eonatology
DENMARK

EMPATHIC - N - DK

Kære forældre

Med dette spørgeskema "Jeres erfaring tæller" vil vi gerne vide, hvordan I har oplevet indlæggelsen på Neonatalklinikken.

Formålet med spørgeskemaundersøgelsen er at anvende jeres og andre forældres feedback til at forbedre plejen og behandlingen til indlagte børn og familier.

Det er naturligvis frivilligt at deltage. Ved at udfylde og indsende spørgeskemaet giver I jeres samtykke til at deltage i undersøgelsen.

For at mindske antallet af spørgsmål, indhenter vi supplerende oplysninger om fx. fødselsvægt, indlæggelsesvarighed og gestationsalder fra jeres barns journal.

Jeres svar og oplysninger fra journalen vil blive behandlet fortroligt, og undersøgelsen er anmeldt til Datatilsynet, som fører tilsyn med persondataloven.

Nummeret på side 2 er med for, at holde rede på, hvem der har svaret. For at få pålidelige resultater er det vigtigt, at så mange som muligt udfylder skemaet. Vi udsender derfor en påmindelse til alle, vi ikke har modtaget svar fra efter ca. 2 uger.

Har du spørgsmål om undersøgelsen, kan du læse mere på Neonatalklinikkens hjemmeside:

www.neonatal.rh.dk. Du er også velkommen til at ringe på telefon 35450931 eller sende en e-mail til: sanne.allermann.beck@regionh.dk

På vegne af alle sygeplejersker og læger på Neonatalklinikken, vil jeg gerne takke jer for jeres deltagelse.

Sanne Allermann Beck, Projektansvarlig

Sådan udfyldes spørgeskemaet:

Indledningsvis bliver der stillet et par generelle spørgsmål. Derefter følger der nogle udsagn, der omhandler jeres oplevelser. Hvis I er enige i udsagnet, sætter I kryds mod højre, hvis dette ikke er tilfældet, sætter I kryds mod venstre.

Det er muligt, at et udsagn ikke er relevant for jer. Sæt i det tilfælde et kryds i kolonnen 'Ikke relevant'.

Eksempel:

	Meget UENIG					Meget ENIG	Ikke relevant
Vi fik en kop kaffe hver dag	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vi kunne altid opbevare vores personlige ejendele sikkert	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Der var altid en ledig parkeringsplads	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

På den sidste side kan I, på baggrund af jeres oplevelser, komme med ideer til forbedringer.

1. DEL: GENERELLE SPØRGSMÅL

I denne del stilles der nogle generelle spørgsmål om jer og jeres familie.

Hvem udfylder spørgeskemaet?

- Mor
- Far
- Både mor og far
- Andre:

Hvilken kulturel baggrund passer bedst til jeres familie
(Flere svar er mulige)

- Dansk
- Tyrkisk
- Polsk
- Rumænsk
- Pakistansk
- Anden, hvilken:

Hvad er den højeste uddannelse I har gennemført?

Mor Far

- | | | |
|--|--------------------------|--------------------------|
| Ingen | <input type="checkbox"/> | <input type="checkbox"/> |
| Folkeskole (7.-10. klasse) | <input type="checkbox"/> | <input type="checkbox"/> |
| Erhvervsfaglig uddannelse (f.eks. tømrer, elektriker, salgsassistent) | <input type="checkbox"/> | <input type="checkbox"/> |
| Gymnasial uddannelse (f.eks. STX, HF, HTX, HHX) | <input type="checkbox"/> | <input type="checkbox"/> |
| Kort videregående uddannelse, under 3 år (f.eks. laborant, markedsføringsøkonom) | <input type="checkbox"/> | <input type="checkbox"/> |
| Mellemlang videregående uddannelse, 3-4 år (f.eks. diplomingeniør, pædagog, folkeskolelærer) | <input type="checkbox"/> | <input type="checkbox"/> |
| Lang videregående uddannelse, over 4 år (f.eks. læge, civilingeniør) | <input type="checkbox"/> | <input type="checkbox"/> |

2. DEL: FORÆLDREOplevelser

I denne del af spørgeskemaet vil vi gerne vide, hvordan I har oplevet plejen på Neonatalklinikken. Hvis I er enige i et udsagn, sæt da et kryds mod højre, hvis det ikke er tilfældet, så sættes krydset mod venstre. Det er også muligt, at et udsagn ikke er relevant for jeres situation. Sæt i det tilfælde et kryds i kolonnen 'Ikke relevant'.

INFORMATION	Meget UENIG					Meget ENIG	Ikke relevant
Vi havde dagligt samtale med lægerne og sygeplejerskerne om plejen og behandlingen af vores barn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vores spørgsmål blev klart og tydeligt besvaret af læger og sygeplejersker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Læger og sygeplejersker gav enslydende information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hvis vores barns tilstand blev forværret, blev vi straks informeret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vi fik klar og tydelig information om vores barns situation af læger og sygeplejersker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne informerede os klart og tydeligt om behandlingen til vores barn – og eventuelle følger	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne gav klar og tydelig information om undersøgelser og indgreb	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne gav klar og tydelig information om medicinens virkning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne gav information om vores barns fremtidsperspektiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Informationsmaterialet, som vi fik udleveret om plejen, var forståeligt og fyldestgørende beskrevet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Den information vi fik af læger og sygeplejersker var fuldt ud forståelig for os	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne gav os ærlig information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PLEJE OG BEHANDLING

Meget
UENIG

Meget
ENIG

Ikke
relevant

Lægerne og sygeplejerskerne havde et godt samarbejde	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne var opmærksomme på at forebygge og/eller behandle smerter hos vores barn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne er kompetente; de ved hvad de gør	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Den rigtige medicin blev altid givet til tiden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne var informerede om vores barns sygehistorie ved indlæggelsen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne var opmærksomme på vores barns udviklingsstadiet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hvis vores barns tilstand blev forværret, handlede lægerne og sygeplejerskerne med det samme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Der blev reageret godt på vores barns behov	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne arbejdede efter den samme målsætning: Den bedste pleje og behandling for vores barn og for os	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne var meget opmærksomme på vores barns velbefindende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vi vidste hver dag hvilke læger og sygeplejersker, der havde ansvar for vores barn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vi fik følelsesmæssig støtte af lægerne og sygeplejerskerne	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne var opmærksomme og reagerede på vores behov	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne var omsorgsfulde både overfor vores barn og os	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I akutte situationer var der altid en sygeplejerske, der støttede os	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sygeplejerskerne sikrede sig altid, at vores barn lå rart og velplejet i kuvøsen / sengen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overflytningen fra Neonatalklinikken til den modtagende afdeling forløb godt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

FORÆLDREDELTAGELSE

Meget
UENIG

Meget
ENIG

Ikke
relevant

Vi blev aktivt medinddraget i beslutninger vedrørende behandlingen af vores barn

Vi blev opfordret og støttet til at være tæt på vores barn

Vi havde tillid til lægerne og sygeplejerskerne

Også under intensive aktiviteter, kunne vi altid være tæt ved vores barn

Sygeplejerskerne opfordrede til og støttede os i at deltage i plejen af vores barn

Sygeplejerskerne hjalp os med tilknytningen til vores barn

Vi blev vejledt af sygeplejerskerne i plejen af vores nyfødte barn

Vores barns pleje blev drøftet med os inden overflytning/udskrivelse

ORGANISATION

Meget
UENIG

Meget
ENIG

Ikke
relevant

Vi følte os trygge under opholdet på Neonatalklinikken

Vores barns kuvøse/seng var ren

Lægerne og sygeplejerskerne arbejdede målrettede

Det var let at komme i telefonisk kontakt med Neonatalklinikken

Der var tilstrækkelig plads omkring vores barns kuvøse /seng

Neonatalklinikken var ren

Lyden på Neonatalklinikken var dæmpet så meget som muligt

Der var en god atmosfære på Neonatalklinikken uden uvenlig adfærd

DEN PROFESSIONELLE ATTITUDE

Meget
UENIG

Meget
ENIG

Ikke
relevant

Lægerne og sygeplejerskerne præsenterede sig altid med navn og funktion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne udviste empati og medfølelse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne arbejdede hygiejnisk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne sørgede for privatliv til os og vores barn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne udviste respekt for vores barn og os	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne førte ingen unødige samtaler ved vores barns kuvøse/seng	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Der var en god stemning blandt personalet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne udviste varme og gav os følelsen af at være velkomne	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
På trods af travlhed fik vi og vores barn tilstrækkelig opmærksomhed fra lægerne og sygeplejerskerne	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Der blev taget højde for vores kulturelle baggrund	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne prioriterede altid vores barns sundhedstilstand og trivsel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lægerne og sygeplejerskerne havde altid tid til at lytte	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

GENERELLE OPLEVELSER

Meget
UENIG

Meget
ENIG

Vi vil anbefale denne neonatalafdeling til andre, der kommer i en
tilsvarende situation

Hvis vi skulle komme i den samme situation igen, vil vi gerne tilbage til
denne neonatalafdeling

Hvilken score vil I give os for indlæggelsesforløbet i sin helhed?

Meget dårlig 1 2 3 4 5 6 7 8 9 10 Fremragende

Læger

Sygeplejersker

Hvis I vil uddybe, kan I skrive det herunder

Vi vil gerne lære af jeres oplevelser. I kan bruge rubrikkerne herunder til at fortælle jeres historie.

Jeres oplevelser vedrørende MODTAGELSEN OG INDLÆGGELSEN i Neonatalklinikken

Jeres oplevelser UNDER selve indlæggelsen

Jeres oplevelser i forbindelse med OVERFLYTTTELSEN/UDSKRIVELSEN

Jeres GENERELLE oplevelser

Spørgeskemaet kan I sende retur i den vedlagte konvolut (Portoen er betalt).

På vegne af alle læger og sygeplejersker i Neonatalklinikken.
Mange tak for jeres deltagelse.

Sanne Allermann Beck, Projektsygeplejerske

Spørgeskemaet er udarbejdet af:

Sanne Allermann Beck, Sygeplejerske, SD, Cand.cur.

Ovenstående har ophavsret til den danske version af "Jeres erfaring tæller" (EMpowerment of PArnts in THE Intensive Care-Neonatology- Denmark (EMPATHIC-N-DK)).

Tilladelse til at anvende spørgeskemaet kan indhentes hos Sanne Allermann Beck, e-mail: sanne.allermann.beck@regionh.dk.

Spørgeskemaet er en oversættelse af: EMpowerment of PArnts in THE Intensive Care-Neonatology (EMPATHIC-N), version:2010/EMPATHIC-N lijst[©]

Latour JM, Duivenvoorden HJ, Hazelzet JA, van Goudoever JB. Development and validation of a neonatal intensive care parent satisfaction instrument. Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies - LA English 2012;13(5):554.