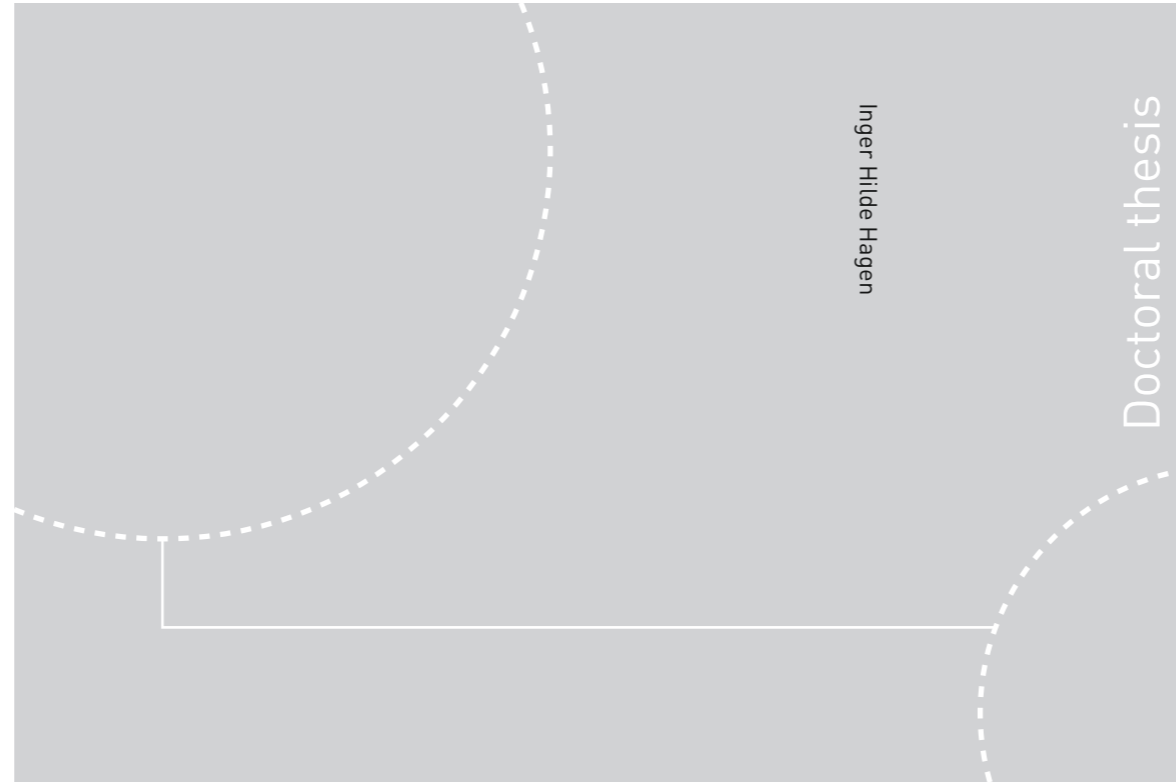


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Inger Hilde Hagen

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Norwegian University of Science and Technology
Thesis for the Degree of
Philosophiae Doctor
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Department of Mental Health

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Trondheim, May 2019

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LIST OF PAPERS

Paper I:

Hagen, Inger Hilde; Vadset, Tove B.; Barstad, Johan; Svindseth, Marit Følsvik. (2015) Development and validation of Neonatal Satisfaction Survey (NSS 13). *Scandinavian Journal of Caring Sciences*. vol. 29 (2).

Paper II:

Hagen, Inger Hilde; Svindseth, Marit Følsvik; Nettet, Erik; Orner, Roderick; Iversen, Valentina Cabral. Validation of the Neonatal Satisfaction Survey (NSS-8) in six Norwegian neonatal intensive care units: a quantitative cross-sectional study. *BMC Health Services Research*.

Paper III:

Hagen, I. H., Iversen, V. C., Nettet, E., Orner, R., & Svindseth, M. F. J. B. H. S. R. (2019). Parental satisfaction with neonatal intensive care units: a quantitative cross-sectional study. *19*(1), 37. BMC Health Services Research. doi:10.1186/s12913-018-3854-7

ACRONYMS AND ABBREVIATIONS

NICU	Neonatal intensive care unit
FCC	Family-centred care
NSS-13	Neonatal Satisfaction Survey (13 factors)
NSS-8	Neonatal Satisfaction Survey (8 factors)
NIDCAP	Newborn Individualized Developmental Care and Assessment Program
PPD	Postpartum depression
PTSD	Post-traumatic stress disorder
GA	Gestation age

DEFINITIONS

A **neonatal intensive care unit (NICU)** is an intensive care unit specializing in the care of ill or premature newborn infants.

An **infant** is the more formal or specialised synonym for "**baby**". The term "infant" is typically applied to young children between one month and one year of age; however, definitions may vary and may include children up to two years of age.

A **newborn** is an infant who is only hours, days, or up to one month old. In medical contexts, newborn or **neonate** (from Latin, *neonatus*) refers to an infant in the first 28 days after birth. The term applies to premature, full-term and postmature infants; before birth, the term "foetus" is used.

Premature birth is the birth of a baby at fewer than 37 weeks of gestational age (1).

Gestational age is a measure of the age of a pregnancy, which is taken from the woman's last menstrual period (LMP) (2).

User satisfaction is the satisfaction dimension, defined as the level at which the user's expectations of the service are met (3).

Quality is defined as "To what extent healthcare for individuals and groups increases the likelihood of the desired health effect and is in accordance with today's professional knowledge" (4).

Kangaroo care is a method of holding a premature baby that involves skin-to-skin contact.

SAMMENDRAG

Foreldrenes erfaringer og tilfredshet med nyfødt intensive avdelinger i Norge: Utvikling og validering av et spørreskjema

Pasienters erfaringer og tilfredshet med helsetjenesten er ansett for å være en av nøkkel målene for kvalitet. Når et barn er født prematurt eller er akutt og kritisk sykt og innlagt i en nyfødt intensiv seksjon, kan det ofte være en traumatisk opplevelse for foreldrene.

Tilknytning mellom foreldre og barn starter ved fødselen, og flere faktorer i en nyfødt intensiv seksjon kan påvirke denne prosessen. Det er viktig for tilknytningsprosessen mellom det innlagte barnet, foreldre og søsken at nyfødt intensiv seksjonene er i stand til å ivareta hele familiens behov. Det er mangel på validerte spørreskjema som dekker forelders tilfredshet med nyfødt intensiv sett ut fra familiefokusert nyfødtomsorg og i henhold til dagens standard og retningslinjer.

I studie 1 (artikkel I) var hensikten å utvikle, pilot-teste og pre-validere et spørreskjema til å måle foreldrenes tilfredshet med nyfødt intensiv seksjonene. Ulike forskningsmetoder ble brukt og studien ble utført i fem steg: a) utvikling av spørsmål hentet fra litteratur, b) intervju av helsepersonell (to ganger), c) intervju av foreldre, d) innsamling av data til pilotstudien og statistisk pre-validering av spørreskjemaet. Dette resulterte i et midlertidig spørreskjema kalt Neonatal Satisfaction Survey (NSS-13) med totalt 69 spørsmål fordelt på 13 kategorier.

I studie 2 (artikkel II og III) ble NSS-13 brukt til å samle data fra seks nyfødt intensiv seksjoner geografisk spredt rundt i Norge. Totalt 568 foreldre besvarte spørreskjemaet, som tilsvarer 45% av totalt mulig respondenter i studieperioden. I artikkel II ble datakvaliteten og de psykometriske egenskapene systematisk vurdert gjennom en eksplorerende faktoranalyse som identifiserte åtte faktorer for måling av tilfredshet: «omsorg og behandling», «legene», «besøk», «informasjon», «fasiliteter», «foreldrenes bekymringer», «utskriving» og «søsken». Alle faktorene viste tilfredsstillende intern konsistens og god reliabilitet, og det ble beregnet en overordnet tilfredshetsskala. Resultater fra artikkel III viste at å motta støtte fra familie og venner var den viktigste sosio-demografiske variabelen for tilfredshet. De viktigste faktorene for foreldrenes tilfredshet med tjenestene som ble tilbudt ved nyfødt intensiv var å bli involvert i beslutningstaking rundt barnets omsorg og behandling, å bli møtt med respekt og empati fra personalet og kontinuitet i omsorg og behandling. Resultatene viser også at

foreldrene har behov for mer informasjon, oppfølging, veiledning og opplæring til å møte barnets behov.

Samlet bidrar denne studien med et godt validert og reliabelt spørreskjema som måler foreldrenes grad av tilfredshet med nyfødt intensiv. Skjemaet kan gi svar på hva foreldrene er fornøyd med i seksjonen og hva som kan gjøres for å bedre helsetjenesten.

SUMMARY

Background and aims

Patient experience and satisfaction with healthcare services is recognized as one of the key measures of quality; therefore, it is essential to assess parents' experiences with neonatal services to understand how these can be improved. When an infant is born premature or is acute or critically ill and admitted to a neonatal intensive care unit (NICU), it will most likely be a traumatic experience for the parents of the infant. Approaching and bonding with a premature or sick infant could be challenging for the parents. The bonding process starts at birth, and several factors in NICUs could contribute this process, either to delaying or strengthening the bonding process. It is important that NICUs are able to give the best care to safeguard the needs of the infant, the parents of the infant and the siblings of the infant to give the best care possible to the infant, to develop parenting abilities, and for emotional bonding with siblings. Increased attention has been given to developing and implementing quality measures. Parent satisfaction should be one of the indicators to ensure that newborns and their families receive the highest quality of care. Previous research is sparse, and there is a lack of validated surveys covering questions concerning family-centred care (FCC) according to today's standards and guidelines. A principal aim of this study was to investigate parent satisfaction in NICUs, which was accomplished first through developing and validating a questionnaire that measures parent satisfaction; second, through exploring factors that influence parent satisfaction; and third, through exploring services in NICUs that are most in need of improvement.

Study 1 (Paper I)

Methods: The purpose of this study was to develop, pilot test and pre-validate a survey to investigate parent satisfaction with neonatal wards in a population of parents with infants admitted to a NICU. Mixed methods were used. The study was carried out in five steps: a) construction of the items from the literature, b) face and content validity by health personnel (two times), c) face and content validity by parents, d) data collection (pilot testing) and data analysis (pre-validation).

Results: The Neonatal Satisfaction Survey (NSS-13) covered 13 subcategories. The subcategories measured parent satisfaction with the neonatal unit according to "staff", "admission", "nurses", "anxiety", "siblings" (parents' perception of caring for the siblings of

the newborn), “information”, “time out”, “doctors”, “facilities”, “nutrition”, “preparation for discharge”, “trust”, and “visitors”. Each subcategory scored an acceptable internal consistency. The full version of the Neonatal Satisfaction Survey contains 69 items, and each subcategory contains between two and eleven items.

Conclusions: The NSS-13 (preliminary survey) is a reliable instrument, but the study population was too small for proper statistical validation. The NSS-13 appears to be suitable for measuring parents’ satisfaction with neonatal units. The questionnaire can be used in full, but can also measure subcategories, such as those that measure parents’ satisfaction with the neonatal unit, which can be used to improve the quality in these wards.

Study 2 (paper II, III)

Methods: The NSS-13 questionnaire was used to collect data from six geographically spread Norwegian NICUs. The data quality and psychometric properties were systematically assessed using exploratory factor analysis, tests of internal consistency, reliability, and construct, convergent and discriminant validity. Each set of hospital survey returns were subjected to attrition analysis before an overall satisfaction rate was calculated.

Results: In paper II, the survey sample of 568 parents represented 45% of the total eligible population for the period of study. Only 1.1% of all returns had >10% missing. The attrition analysis showed congruence between the sample and the total population. Exploratory factor analysis identified eight factors of concern to parents: “care and treatment”, “doctors”, “visits”, “information”, “facilities”, “parent anxiety”, “discharge” and “siblings”. All of the factors showed satisfactory internal consistency and good reliability (Cronbach’s alpha ranged from 0.70-0.94). For the whole scale of 51 items, α was 0.95. Convergent validity using Spearman’s rank between the eight factors and the question measuring overall satisfaction showed significant values for all of the factors. Discriminant validity was established for all of the factors. The overall satisfaction rates ranged from 86 to 90%, while for each of the eight factors, the measures of satisfaction varied between 64 to 86%.

In paper III, support from families and friends was found to be the most important sociodemographic factor for satisfaction. The most important factor for parent satisfaction with NICU services was being involved in decision-making regarding the infant, respect and empathy from staff, and continuity of care and treatment. Parents were least satisfied with

how NICUs facilitated siblings. Parents are in need of more guidance and training in meeting their child's needs, including more information and follow-up.

Conclusion: In paper II, the NSS-8 questionnaire was found to be a valid and reliable scale for measuring parents' assessment of quality of care in NICUs. Statistical analysis confirmed the instrument's capacity to measure parents' experiences of NICUs.

In paper III, the study suggested that health personnel should be aware of parents who lack a good friend and family network, be more attentive to parents with very preterm infants and parents with long NICU admissions, provide support to siblings, and give more attention to parents' need for continuity of care, follow-up, and information.

1 INTRODUCTION

1.1 The importance of investigating and strengthening parent satisfaction with NICUs

It is claimed that satisfaction is one of the core outcome measures for healthcare. Satisfied users/patients are more likely to comply with treatment (5-7) and take an active role in the care process (8). Studies have found positive associations between parent satisfaction with healthcare and their ability to provide need-based care for their child (9, 10). Dissatisfaction is thought to be associated with a poorer postnatal psychological adjustment, more negative feelings towards the infant, and breastfeeding problems (11, 12). It has been determined that parents experience very high stress levels when their infants are admitted to a NICU and that satisfaction with healthcare services may decrease their level of stress (13, 14).

Parenting in the NICU is different and challenging compared to parenting a healthy infant at home. It is normal to experience a range of emotions and changes in behaviour while the newborn baby is in the NICU. Some parents may find it difficult to deal with these feelings. Studies have shown that these parents experience higher rates of psychological distress in comparison to parents of full-term, healthy infants (15-21). Postpartum depression (PPD) and post-traumatic stress disorder (PTSD) are found to be a risk for both fathers and mothers (22-24). Early physical separation from the infant within 24 hours of birth is related to an increase in parents' NICU-related stress (25). The stress experienced by parents during their infant's hospital stay can affect the parent-infant relationship and their ability to bond reciprocally (26).

Involving parents in the care of the infant is reported to reduce stress and increase confidence in parents and also increases satisfaction with the overall care received in the NICU (9, 27-29). Most of the NICUs in Europe are using the family-centred care (FCC) principle in their standard practice to enhance infant-parent relationships and involve the families. Various definitions of FCC are available. Overall, FCC can be summarized as a clinical practice approach that includes some core principles: coordination of care attained by means of effective communication; provision of information and education to the family; respect and understanding; and physical and emotional support and involvement of parents in decision-making and in care (30). FCC is increasingly acknowledged in NICUs and advocates for the active engagement of both parents in the care journey. FCC is acknowledged to be the current gold standard as a medical concept in NICUs (31). Using FCC in NICUs has also been found to reduce the anxiety of the parents of premature infants (28).

The way in which FCC is implemented in healthcare services varies between countries and units. Although this philosophy is used by most of the NICUs today, research shows that there is still room for improvement before it has been firmly rooted across institutions (32). Seriachius et al. (2018) found three key barriers that parents face in terms of being involved in the care of their infant in NICUs (33): a) often feeling like bystanders and not being involved enough, b) the hierarchy between parents and staff, and c) the peripheral role of fathers. Harrison (2010) found in a review study that nurses support the concept of FCC but experience difficulties in implementing this philosophy of care in practice (34). Several barriers to implementing FCC were found, such as lack of time and negative attitudes, including feeling threatened, fearful of losing one's role and feeling intimidated. Lack of support within the healthcare system and from other healthcare disciplines was also listed as a barrier to implementing FCC.

Evaluating parent satisfaction is important in NICU settings, and validated instruments based on FCC principles and monitoring all of its dimensions are recommended (31). The FCC issues need to be identified and integrated into satisfaction surveys to improve clinical practice based on the experiences of the parents (35). Patient and user satisfaction measurements are considered a significant part of quality improvement tools (15, 36, 37). By monitoring user experiences, the hospital units will be more prepared to undertake the necessary changes to improve quality and provide better healthcare services (15). Parental satisfaction with NICU services is crucial because they are disturbed by the appearance and behaviour of their sick or immature infants and by the alterations in their parental roles compared to parents with full-term, healthy newborn infants (21, 38). It is therefore important to monitor not only the needs of the child but also the needs of the parents when admitted to a neonatal unit. The value of measuring satisfaction becomes increasingly important because the public sector requires hospitals to document the quality of care as perceived by the patient/user (39). In addition to patient feedback to improve the quality of care, satisfaction surveys used over time are important to monitor and evaluate the implemented changes.

1.2 Parent and family needs and experiences in the NICU

A lack of comprehensive information for understanding parental needs during stressful periods with a critically ill infant has been reported. In a review, Conner and Nelson (1999) aimed to describe the current understanding and measurement of parent needs and expectations of NICU services, from the time the parents enter the NICU to discharge.

Thirteen categories were identified, and the most frequently regarded as important were information, person-related support, attachment/parenting, physical support, spiritual support, and staff support (40).

The factors mentioned above have not changed dramatically over the last decades. Mundy (2010) found largely the same results as Conner and Nelson, and they also found that the needs of mothers and fathers did not differ significantly (41). Parental needs and experiences in NICU settings have been studied by various methods. The quantitative studies available on this subject used modified versions of the Critical Care Family Needs Inventory (42-44), originally from the adult intensive care setting (45). A review study on the information needs of parents of infants admitted to a NICU found that parents have high information needs. The most important was the need of information at the acute phase (46). In FCC, culturally sensitive care practices and physical environments, such as increased visiting hours, family rooms and optimization of the space in the units should be considered to facilitate parent-infant closeness (26). Researchers evaluating FCC in the NICU have found that parents identify effective communication, straightforward information, individualized care, parent-healthcare provider relationships, parental involvement and continuity/consistency of care as key factors to their satisfaction (47). Furthermore, the presence of health personnel who listen to parents' needs is a component that is repeatedly identified as shaping parent satisfaction with their child's hospitalization experience (12, 48-50).

It is important for healthcare personnel to be concerned with the needs of individual parents because the satisfaction of those needs is essential for infant well-being (43). Giving the parents and their family's privacy is critical when providing patient- and family-centred care, which encourages family members to be more present. The provision of a family area is especially important for the NICU population, as families may live long distances from hospitals, making visitation more challenging (51). Family members should have direct access to the infant and have privacy and adequate space for daily activities. Improving quality necessitates gathering data regarding the parents' experiences with different factors, as well as the level of satisfaction with each factor (52).

Several studies have focused on parent experiences during the stay in NICUs. Al Magharich et al. (2016) conducted a systematic review of qualitative studies and included nine studies from 2007-2014. They found that parents experience stress due to the hospitalization, the

NICU environment and staffing. Additionally, alterations in the parenting roles was difficult, and parents reported many psychological and emotional problems, such as depression, anxiety, sleep disturbance, grief and isolation (53). Earlier life experiences and the infant's condition are important for the experience of the stay in NICU (54). Parents are often characterized by emotions such as anxiety, stigma, guilt feelings, hopelessness, distress, fear, lack of control and many other psychological and emotional issues (10, 54-57).

Parent satisfaction measures based upon both the needs and experiences of parents is important to provide healthcare professionals with adequate feedback on their healthcare provision, and it also increases treatment compliance.

1.3 Studies measuring parent satisfaction in NICUs

1.3.1 Systematic reviews

In recent decades, there have been vast changes in the development of quality and improved standards of care in NICUs. The discipline of neonatal treatment, care and research experienced a paradigm shift in the 1960s. The relatively new discipline of neonatal treatment could be one of the reasons why so few questionnaires have been developed (58, 59). The only review article that was found was Conner and Nelson (1999) (40). They concluded that none of the five satisfaction questionnaires in their review study had been tested for validity and they did not measure parent satisfaction thoroughly. The questionnaires were as follows: The Parent Feedback Questionnaire by Blackington (1995) (60), NIPS by Mitchell-Dicenso et al. (1996) (61), Inpatient Parent Satisfaction, Children's Health Care Minneapolis, by authors not listed, Picker Institute Inpatient NICU, by the Picker Institute Europe (1998) and NICU-PSF (J.M.C.) (authors not listed).

Other articles have described instrument validation without presenting the instrument in full (Mitchell-DiCenso et al. 1996; McPherson et al. 2000, Butt et al. 2009 and Ygge 2001) (62-65). They concluded that topics from the parents' perspective, such as information about the disease, routines and availability of the staff, medical treatment, the care process, staff behaviour, participation, and staff working environment, were important areas to be considered when preparing questionnaires. The primary aim of the review by Butt et al. (2013) was to synthesize findings from the published empirical literature on parent satisfaction with care in NICUs, not to find reliable and validated instruments (66). Therefore, the studies varied in their study design and methods. They found twelve studies published between 1990 and 2011 and showed that many of the instruments lacked strong psychometric properties.

Most of the parent satisfaction instruments have not been based on FCC principles and philosophy. Dall'Oglio et al. (2017) undertook a systematic review of instruments for assessing parent satisfaction with FCC in NICUs (36) and found eleven new instruments, published from January 2006 to March 2016. Most of the instruments were not tested for validity and reliability. They concluded that only two studies validated a parent satisfaction questionnaire and included all six of the FCC principles. One of the two instruments was the one published from the pilot study of this thesis (NSS-13 from study 1) and is the only questionnaire developed in Scandinavia (67). The other instrument (EMPATHIC-N) was developed by Latour (2012) from The Netherlands (68) who was one of the authors of the systematic review (36). The pilot study of NSS-13 in this thesis was about to be finished in 2012, and when comparing the two questionnaires it was found that Latour's questionnaire, in many ways, covered the same topics as the instrument from our pilot study. This can be seen as a strength for both questionnaires.

In addition to the existing literature, three review studies of parent satisfaction questionnaires have been published to date (40, 66, 69). In the past two decades, the care, philosophy and medical treatment of neonatal intensive care units has changed (70). After analysing the studies in the abovementioned reviews, they reported missing and inadequate reliability and validity testing in most of the instruments; additionally, some of the questionnaires were developed as far back as the 1990s. A new search/update was carried out for the time period from January 2008 to June 2018. The aim was to search for validity- and reliability-tested questionnaires that measured parent satisfaction with NICUs and for studies that had modified older questionnaires. A total of seven questionnaires were identified (table 1). Three instruments developed within the last ten years were found. The first instrument was from The Netherlands in 2012, EMPATIC-N (68), and was developed to measure parent satisfaction in NICUs. The second (P-BESS) was from the UK in 2014, and it was developed to measure the NICU experiences and satisfaction of parents with very premature infants (71). The third (NPSQ) was from Iran (2016), and it measured the parent satisfaction of developmental care in NICUs (72).

1.3.2 Primary studies

The last four articles were studies that adapted and modified older instruments. The first was a study from Australia that modified the Nurse Parent Support Tool (NPST), developed by Miles (73, 74). The second one was from the USA, modifying the Nurse Parent Support Tool (NPST), also developed by Miles (75). The third questionnaire was from the UK in 2014 (76). The authors modified the Picker Institute Inpatient NICU. The fourth instrument was from Iran in

2015, and the authors modified a questionnaire based on a parental satisfaction instrument from PICU (table 1).

Table 1 Studies on parent satisfaction in NICUs

Development and validation studies from 2008-2018				
Author(s) and year	Aim	Method-Design	Sample size and setting	Instruments
Latour et al. (2012) (68)	To develop and test the psychometric properties of the EMPATIC-N questionnaire measuring parent satisfaction.	A psychometric study	279 parents of infants hospitalized in a 30-bed university NICU, divided into two cohorts. Parents completed the questionnaire 3-4 weeks after discharge. (The Netherlands)	Empowerment of Parents in The Intensive Care-Neonatology (EMPATHIC-N) questionnaire of 57 items in 5 domains.
Sawyer et al. (2014) (71)	To develop a questionnaire to assess parent experiences and satisfaction with care during very preterm birth.	A questionnaire development study	147 parents of infants born before 32 weeks of gestation. Five tertiary care centres in England. No. beds not reported. Parents completed the questionnaire approximately 9 months after the birth (UK)	The preterm birth experience and satisfaction scale P-BESS with 17 items.
Rafiey et al. (2016) (72)	To develop and test the psychometric properties of a tool for measuring parent satisfaction of developmental care in the NICU.	A psychometric methodological study	400 parents of infants hospitalized in 34 type III NICUs in Tehran. No. beds not reported Parents completed the questionnaire at their infant's discharge. (Iran)	The NICU parent satisfaction questionnaire (NPSQ) with 59 items.
Studies that adapted and modified an older instrument, from 2008-2018				
Author(s) and year	Aim	Method-Design	Sample size and setting	Instruments
Tran et al. (2009) (74)	To identify parents' perception of the type (emotional, informational, appraisal and instrumental) and level of support provided by nurses in NICUs. Parents were asked to rate their level of satisfaction with this support.	A quantitative, descriptive study design	62 parents of preterm infants from 1 level III NICU. No. beds not reported. (Australia)	Modified Nurse Parent Support Tool (NPST) previously developed by Miles (73).

Domanico et al. (2010) (75)	To compare satisfaction levels of families and healthcare staff across different NICU facility designs (open bay, single-family room; SFR).	Prospective study	161 parents of infants divided into three groups. 161 staff members from 1 NICU. No. beds not reported. (USA)	Modified Parent Questionnaire: NPST with 32 items, Likert-scaled adaption of a previously validated questionnaire by Miles (73).
Burger et al. (2015) (76)	To investigate the experiences of the parents who use their services to make improvements to the care.	A quantitative, descriptive study design	6000 parents from 88 NICUs. (UK)	Picker Institute Inpatient NICU.
Bastani et al. (2015) (29)	To determine the effect of family-centred care, including maternal participation, presence, and information about neonatal care, on maternal satisfaction and neonatal readmission.	Randomized clinical parallel trial with a prospective post-test two group design.	110 mothers of preterm infants with respiratory distress syndrome from 1 NICU of a university maternity hospital. No. beds not reported. (Iran)	The questionnaire was modified based on the parental satisfaction instrument from PICU.

1.3.3 Quality assessment

The primary purpose of four of the studies was to evaluate the degree of parent satisfaction with the NICUs, and in this case, they modified previous questionnaires (29, 74-76). After a systematic review, it was found that two of the studies only monitored nurse support (74, 75), while the other two did not report validity and reliability testing results. Only three studies aimed to develop and test a questionnaire to measure parents' degree of satisfaction with care in the NICU (68, 71, 72). They are from The Netherlands, Iran and the UK (table 1).

One strength of the studies of NICU parent satisfaction questionnaires, which increase the generalizability of findings, is that most are conducted in an almost equal order as is recommended in questionnaire development literature (77-80). All instruments aimed to develop and validate a questionnaire that was developed through a structured process that included a review of the literature for relevant questions and discussions with relevant experts, such as healthcare personnel from NICUs and the parents of infants admitted to a NICU. All of the instruments presented in table 1 are self-administered questionnaires and were sent by post or mailed to the parents immediately before or after discharge from the NICU. In six of the seven questionnaires, the items in the satisfaction questionnaire were categorized into factors. The 19 identified factors were generally related to three major issues: information and attitude issues, clinical care issues and organizational issues (table 2).

Table 2 Categories used in satisfaction questionnaires from the primary studies presented in table 1

General issues	Factors (reference number)
Information and attitude issues	Information, professional attitude (68) Information and explanations (71) Information (72) Informational support (74) Information about neonatal care (29) Parental education (72)
Clinical care issues	Care & treatment (68, 72) Staff professionalism and empathy (71) Appraisal support, emotional support (74) Staff performance (75) Parental participation (29, 68, 72) Partner involvement, confidence in staff (71)
Organizational issues	Organization (68) Hospital facilities (72) Instrumental support (74) Physical facility (75)

However, there are several threats to the validity of findings in questionnaire development studies. Bias can occur at any phase of research and be introduced either from the designers or from responders of a survey (80, 81). Bias from designers often occurs when constructing the instrument. Bias can be problems with wording, which can be misunderstood, leading questions, incomplete data and use of faulty scales (80). Type of question, language used, and order of items may all bias responses, and to avoid this, consideration should be given to the order in which items are presented. Presenting controversial or emotive items at the end of the questionnaire and boredom, demographic or clinical data at the end can minimize the bias. None of the studies mentioned where the demographics and clinical data were placed in the questionnaire.

Several forms of bias may also occur from the respondents (82). The responders first need to understand the question, and in this case, all authors of the three questionnaires aiming to develop and validate a questionnaire (68, 71, 72) have tried to avoid this bias by using experts in the field to read the questions (content and face validity, table 3). Another way to reveal such bias is to estimate the number of missing items of the returned questionnaires. If the level of missing data is low, the explanation might be that the questionnaire is acceptable to respondents. In the abovementioned studies, none of them reported missing (68, 71, 72).

Table 3 Characteristics of the satisfaction questionnaires

Name of instrument (reference No.)	Name and number of factors	Number of items	Validity testing	Reliability testing	Scales	Distribution
Empowerment of Parents in The Intensive Care-Neonatology (EMPATHIC-N) (68, 83)	5 domains; Information Care & Treatment Parental Participation Organization Professional Attitude	57 statements	Content and face validity. Structural equation modelling and confirmatory factor analysis.	Reliability: (Cronbach α ranged from 0.82 to 0.95) and reliability across time between two cohorts (did not vary). Congruent validity; no differential validity.	6-point Likert scale 1 (certainly no) to 6 (certainly yes)	Mailed 3-4 weeks after NICU discharge
The Preterm Birth Experience and Satisfaction Scale (P-BESS) (71)	4 factors; Staff professionalism and empathy Information and explanations Confidence in staff Partner involvement	20 statements	Content, face, construct and convergent validity.	Reliability: (Cronbach α ranged from 0.77-0.94; total scale α 0.92).	5-point Likert scale 1 (strongly disagree) to 5 (strongly agree)	Posted and completed approximately 9 months after the birth.
The NICU Parents Satisfaction Questionnaire (NPSQ) (72)	5 factors; Care and treatment Information Hospital Facilities Parental education Parental participation	69 items	Construct validity	Reliability: (Cronbach α ranged from 0.88-0.97) and test-retest was calculated.	6-point Likert scale 1 (denoting the least satisfaction) to 6 (denoting the greatest satisfaction).	At time of discharge
Modified Nurse Parent Support Tool (NPST) (74).	4 domains; Emotional support Information support Appraisal support Instrumental support	21 items	Not psychometrically tested as reported by authors.	Not psychometrically tested as reported by authors.	5-point Likert scale Rating not mentioned.	Prior to discharge
Modified Nurse Parent Support Tool (NPST) (75).	2 topics/categories; Staff performance Physical facility	31 questions	Not reported	Not reported	5-point Likert scale 1 (almost never) to 5 (almost always)	Around the time of their infant's discharge

Picker Institute Inpatient NICU (76)	Not described	Not mentioned	Content and face validity, but results not reported.	Not reported	Not described	Posted within 8 months to parents who had been discharged back home.
Modified Parental Satisfaction Instrument (29).	3 aspects of parental satisfaction; Parental presence Participation in neonatal care Information about neonatal care	18 items	Not reported	Not reported	5-point graded scale 0 (very dissatisfied) to 4 (very satisfied).	24 hours after NICU hospitalization

Selection bias may occur during identification of the study population, and the risk of selection bias can be particularly high in retrospective cohort studies (81). To prevent this form of bias, it is important to have proper inclusion criteria. The first instrument in table 1, EMPATHIC-N, focused on all parents except parents whose child's hospitalization was <48 h and whose child died in the unit (68). The second instrument (P-BESS) focused on parent experiences and satisfaction with care during very preterm or preterm birth, not on all infants admitted to a NICU (71). Finally, the third (The NICU Parents Satisfaction Questionnaire) focused on parents whose infant was hospitalized for at least 3 days in a NICU. The exclusion criteria were parents whose infant had congenital malformations or surgical procedures (72). The inclusion criteria can also influence the use for whom the instrument is validated for. For example, the P-BESS questionnaire was only validated to use on parents of very preterm infants, not on parents whose infants were born mature or post mature.

Bias due to cultural differences, education level and gender can occur both from interpretation of the questions and in the responses. Therefore, it is important to develop the questionnaire in the same cultural context and in the same cohort in which it is meant to be used. The EMPATHIC-N is developed in a Dutch context (68). The NPSQ is developed in an Iranian cultural context (72) and the P-BESS in a British context (71). Two of the studies (68, 71) reported recruitment of both fathers and mothers, and the other did not report this (72).

Social desirability is also a well-known phenomenon and can lead to bias. In this case, parents can feel loyalty to the health personnel and want to appear as good parents; therefore, they may answer more positively to the questions. Recall ability is another cognitive source and a type

of information bias which is a major issue in studies using self-reporting, such as retrospective cohort studies (80). “Recall bias refers to the phenomenon in which the outcomes of treatment (good or bad) may colour subjects’ recollections of events prior to or during the treatment process” (81. p4). Factors as emotionally stressed situations, complexity of the task and interview length all can contribute to respondent burden in survey research and decrease and bias the response rate; additionally, stress and social desirability could influence respondents to over- or under-report the answers (80, 82). As described in table 1, all of the seven studies varied in the time when the parents completed the questionnaire. In a validation process, the time of answering the questionnaire could bias the results with an inaccurate reporting of the level of satisfaction if the survey is presented at an early stage, or decreased response rates and inflated satisfaction levels if the survey is answered close to discharge. To avoid social desirability bias and minimize the change of response bias, some strategies are recommended, such as the use of self-administered questionnaires (84), designing a mixture of both negative and positive loaded questions, and having objective or neutral questions (e.g., “in what degree did you get the information you need about...”). Such indicators are referred to as indirect measures of satisfaction because they do not directly ask respondents about how satisfied they are (7, 85). In this case, all of the questionnaires were self-administered, but the wording of the items varied. To minimize the danger of response bias, a mixture of both negatively and positively worded items are recommended (79). In the EMPATHIC-N (68) questionnaire, there was only positively worded statements; the P-BESS contained a mixture (71). The Picker Institute Inpatient NICU questionnaire had objective formulated questions (76). The other four studies did not report how the questions were formulated (29, 72, 74, 75).

Bias can also occur in the validation process and in the reliability testing of a questionnaire. The reliability and validity of the satisfaction questionnaires were described in all three of the articles that aimed to develop and validate a questionnaire (table 3). The methods used in testing the psychometric properties of the instrument were diverse. Reliability refers to the repeatability, stability or internal consistency of a questionnaire (79). Overall, the interclass correlation coefficient alpha or Cronbach’s alpha was used in all three studies to establish internal consistency. A corrected item-total correlation is used to measure whether the items measure the same underlying concept by investigating how each item correlates with the total score. Deleting all items <0.3 or >0.8 is recommended (79). Just one study reported this (71). The “alpha if item deleted” metric is also useful if one is developing a scale by comparing the individual questionnaire items with the final alpha value obtained. If any of the values in the

group are higher than the final alpha value, one may want to consider removing this item from the scale (86). Alpha if item deleted was not reported in any of the studies. Reliability across time (test-retest) among the same group of respondents is used for assessing stability of a measure over time and is particularly important if the intended use of the measure is to assess change over time or responsiveness. None of the three studies had tested this form of reliability, but in the EMPATHIC-N study they reported reliability across time between two cohorts (68).

Validity refers to the degree to which an instrument measures what it is intended to measure (77, 79). The authors of the first four studies presented in table 3 established face and content validity mainly by reviewing the literature and using either a Delphi study or focus groups of experts in the field. Construct validity relates to how well the items in the questionnaire represent the underlying conceptual structure. To determine if an instrument has construct validity, the instrument must have strong content validity relative to the construct to be tested and a defined theoretical context. Two of the four instruments reporting validity testing in table 3 measured this by exploratory factor analysis (EFA) (71, 72), and the other used structural equation modelling (SEM) and confirmatory factor analysis (CFA) (68). Convergent, concurrent, criterion, and discriminant validity must also be demonstrated by correlating the measure with related and/or dissimilar measures (12, 79, 80). The form of validity predicting how well the questionnaire correlates to another validated instrument (gold standard) was not tested in any of the studies due to the lack of similar validated satisfaction instruments. Two of the studies tested convergent validity by examining the relationship between the instrument scale and the questions measuring overall satisfaction with care (68, 71). Currently, there is only one developed questionnaire that covers all parents of premature or sick newborn infants with the aim of measuring parent satisfaction with the NICU; it covers FCC principles and is validated in a European culture (68). This instrument is from The Netherlands, and there may be some cultural differences in the organization and functioning of NICUs between the Dutch culture and in Norwegian/Scandinavian countries.

1.3.4 Development and validation of a new questionnaire in Norway - NSS 8

The need for a new questionnaire to measure up-to-date standards of NICUs in Norway was identified as an important goal. When the first study (pilot study (67) was started in 2009, questionnaires that has been developed to measure parent satisfaction with NICU services were searched for. The objective of the search was to find validated instruments used for such surveys, and possibly access the questionnaires themselves. The search also looked for

published results of such surveys, as well as literature not older than 10 years. The data for the present thesis was collected during a nine-year process, in which different stages of the development and validation of a new questionnaire were carried out. This design made it possible to investigate what the crucial factors are when developing a questionnaire. The present thesis adds to the existing parent satisfaction literature by developing and validating a new questionnaire that is suitable to measuring parent satisfaction with NICU care and was developed within the FCC principles and covers current guidelines and legislation. The questionnaire was developed to investigate parent experiences and satisfaction with NICUs in Norway, which could lead to a better understanding of how parents with premature and sick newborns admitted to a NICU experience treatment from health personnel in this vulnerable time of their lives. The questionnaire is also an instrument that can be used for evaluating and improving healthcare services in NICUs.

1.5 The concept of patient and user satisfaction with healthcare

Theoretical perspectives

Satisfaction can be described as a patient/user reaction to several aspects of their service experience (87). There are many and conflicting definitions of patient satisfaction in the literature. The major patient satisfaction theories were all published during the 1980s; almost all research since then has been based on these. Linder-Pelz defined patient satisfaction as “positive evaluations of distinct dimensions of the healthcare” (88 p 578), and stated that patient satisfaction was mediated by personal beliefs and values about care, as well as prior expectations of the care. Fitzpatrick and Hopkins (89) argued that expectations were socially mediated, reflecting the health goals of the patient and the extent to which illness and healthcare violated the patient's personal sense of self. Finally, Donabedian (8) postulated that satisfaction is based on personal relationships in the context of the healthcare system, the outcome of treatment and by the values of the patient. Consistent with this, subsequent research has shown that the dominant predictor appears to be the patient–practitioner relationship, mediated by expectations of this relationship, prior experiences, and health outcomes (7).

Satisfied users are often seen in connection with good quality of the services delivered (37, 90). Questionnaires gathering user experiences and satisfaction are subjective measures, with no definite relationship to external realities. Satisfaction is a broad and often ill-defined concept, defined in many ways (91-93). Satisfaction is generally recognized as multi-

dimensional in nature; there is no consensus about exactly which factors should be included or which are most important (93). Two persons given the same treatment and stimuli will not perceive these services as being exactly similar. Several researchers have called attention to the lack of conceptual agreement in the field of patient and user satisfaction research (94-96). We also find that the credibility of patient and user evaluations do not necessarily rely on any agreement about professionally defined outcome measures. Studies have maintained that patients and those offering the service view quality differently (97-99) and that both views should be considered in quality assessments. The quality of service will be influenced by several different conditions related to patient needs, professional practice and coordination of the individual organizational units in the health and care services (100). Quality consists of elements that change over time and that are emphasized and evaluated differently, depending on the respondent's point of view and perceptions. The concept of quality is value-laden and subjective at the same time, and various elements may often conflict with each other. Quality is not just about the effect of treatment, but about dignity, vision of life, proximity to home and relatives, risk of injury and other unintended effects, and various treatment options (39).

User experiences are part of the conceptual framework for the Quality Indicator Project for the Nordic Council, the Organisation for Economic Co-operation and Development (OECD) and the World Health Organization (WHO). Documents from central health authorities establish that an important feature of excellent quality is that the services involve the users and give them influence. Both the quality indicator projects in the OECD and the Nordic Council of Ministers have user experiences as a central focus area, and the EU also emphasizes this in its conceptual quality framework (90). Norwegian national guidelines give directions to health personnel regarding support to parents. This is a step towards supporting parents as the best possible caregivers for their children. The importance of systematic gathering of user experiences is emphasized by Norwegian care plans as an important tool to improve quality, for innovation and for research. The gathering of systematic user surveys is also regulated by the government in Norway (39).

1.6 Which factors influence parent satisfaction?

A variety of factors is crucial when measuring satisfaction and quality of healthcare in NICUs. In a study from California, McCormick et al. (2008) measured mothers' satisfaction and found that the main predictor of satisfaction with NICU care is child health at the time of interview. They also found that the mother's education level, age, and ethnicity are significant

predictors of satisfaction. Older, more educated, and white mothers were more satisfied with healthcare compared to non-whites and those with a lower family income (101). By contrast, a study from Canada revealed that the mother's age and education level are not significantly associated with satisfaction scores (102). Tsironi (2012) found that parent gender and the duration of infant hospitalization are the most significant factors for parental satisfaction (103). In their review study, Butt et al. (2013) found that few studies have been performed to measure factors related to parental satisfaction with NICU care, coinciding with the limited consensus over which parental or child demographic variables are correlated with satisfaction (66). There is growing evidence that organized support from peer-to-peer and NICU staff is beneficial for NICU parent satisfaction (104, 105), but there is sparse research about what support from family and friends means for parents. The relationship between health personnel and parents is reported to be a key factor in parent satisfaction with care in NICUs (106).

1.6.1 What are parents most satisfied with in NICUs?

A systematic review from 2013 of parent satisfaction with care provided in the NICU shows that most of the parents were highly satisfied with the care they and their infants received. However, this review was based on studies that used instruments not reported to have proper validity and reliability, and some of them focused only on nurse-parent support. Most satisfied were the parents with a high degree of nurse/neonatologist interaction, nurse-to-parent communication and nurse-to-parent support. To optimize parent satisfaction, interventions with families should be congruent with FCC and acknowledge the family rather than the individual members, but the reviewers' called for better instruments for measuring parent satisfaction (66). Martin et.al (2016) also reported similar findings as the review from Butt et al. (2013) (49). The validity, reliability and number of items in the survey used in Martin et al. (name not reported) was not reported. Currently (June 2018), no new articles have been found that measure parent satisfaction with NICU services using validated and reliable instruments based on today's standards.

1.7 Summary of previous research

- There is considerable variability in the findings of previous satisfaction studies, suggesting that more knowledge is needed.
- Being parents to an acute and critically ill newborn or premature infant can be experienced as traumatic for the whole family.
- FCC is acknowledged in NICUs, advocating for the active involvement of the parents as well as their families in the care journey and is essential for infant well-being. FCC has been found to increase satisfaction and decrease readmission, but is not consistently implemented into practice.
- There seems to be agreement on what parents need when their infant is admitted to a NICU.
- There is a lack of validated questionnaires measuring parent satisfaction with the current standards of NICUs.
- Factors associated with parent satisfaction with NICUs are sparsely researched, and there is limited consensus over which parental or child demographic variables are correlated with satisfaction. There is little research on what support from family and friends means for parents.
- Few studies have investigated parent satisfaction regarding FCC in NICUs because of the lack of suitable instruments.

1.8. Aims of the thesis

This thesis aimed to develop and validate a questionnaire to measure parent satisfaction with NICU services and to explore the variables that may influence parent satisfaction with NICUs. This thesis is based on data from two studies:

Study 1 (Paper I) was a pilot test and pre-validation study of a questionnaire with an exploratory design and was carried out in five steps: a) construction of the items from the literature, b) face and content validity by health personnel (two times), c) face and content validity by parents, d) data collection (pilot testing) and data analysis (pre-validation). Study 2 (Paper II and III) was the validation study and had a cross-sectional, exploratory and prospective design.

The following research questions were investigated:

- a) To develop and validate a questionnaire to measure the level of satisfaction with the healthcare services in NICUs.
- b) To validate the Neonatal Satisfaction Survey (NSS-13) in a multicentre population in Norway.
- c) To investigate associations between parent satisfaction and socio-demographic variables.
- d) To investigate associations between parent satisfaction and neonatal intensive care services.

2 MATERIAL AND METHODS

2.1 Study 1: Questionnaire development and pilot testing study (Paper I)

2.1.1 Design.

The study was designed to develop, pilot test and pre-validate a questionnaire, which was intended to investigate the degree of parent satisfaction with NICUs. The exploratory design was based on triangulation of qualitative and quantitative methods.

2.1.2 Procedures and questionnaire building

In the process of developing a questionnaire, it is important to investigate what the questionnaire measures and in what ways it can be useful for the practical field.

The literature search did not find suitable instruments to use when measuring parent satisfaction with NICUs according to today's standards of instrument development, covering FCC-principles. Therefore, a new questionnaire was developed to conduct the survey. First, a literature review was conducted. Second, focus group interviews were carried out with health personnel and with parents who had previous experience of having infants hospitalized in NICUs. Finally, a pre-validation of the questionnaire in a smaller population of parents who had their infants hospitalized in a NICU was conducted (pilot study). The pilot study can give information about feasibility and identify modifications that are needed in the design of a larger study. The aim of the pilot study was to gather information about the structure of the survey and to explore optimal ways of administrating a larger study, and finally, to do a factor analysis for construct validation.

Literature review

First, a review of the literature was undertaken to gather survey questions and to search for questionnaires already existing in the field, as recommended for questionnaire development (77, 79). Very few instruments regarding the NICU population were found, and they were considered unsuitable for the purposes of this study. These instruments were developed some years ago, and the technological improvements and the medical treatment in NICUs has undergone a tremendous development over the past decade (40, 63, 65). In Norway, Garrat et.al (2006) had developed a questionnaire to investigate parent satisfaction with paediatric wards (PEPC) (107). The PEPC instrument seemed to be based on the Norwegian Directorate for Health Quality Indicators. Several of the items from this questionnaire were found to be useful also in a population of NICU parents. Our first preliminary version of the Neonatal Satisfaction Survey (NSS) was based on some of the items in PEPC. In the new questionnaire, we used 15 questions and 10 demographic questions that were all from the PEPC, plus an

additional two overall questions. These questions were about the following situations: *One doctor mainly responsible, Permanent group of nurses, Staff collaboration, Care was well planned, Took account of family situation, Help and support to child, Gave information on parents' responsibility, Caring for child, Caring for parent, Interested in your opinions, Gave adequate explanations, Competence, Information about tests and examinations, Information-discharge* and finally, *information if child falls ill*. The two overall questions were about *Satisfaction with the treatment of the child* and *Satisfaction with how you as a parent were treated*. The questions from the PEPC seemed to include many of the same topics that were found in the literature review (40). Cleveland (108) and FCC principles (109, 110) support the fact that several of the items in Garrat et al (107). were also relevant in a NICU. A search for studies was conducted with the aim to investigate what is important to parents when having their infant hospitalized in a NICU, and several studies helped us to generate single items in our survey (40, 54, 63, 65, 111, 112). Several studies used the word *Experiences* instead of *Satisfaction* because general satisfaction studies seem to generate an over-reporting of positive responses, and asking for experiences implies more solid, concrete areas that are associated with treatment and care, and thus have a larger potential for improvement (93, 113, 114). This ensured the existence of the proposed underlying theoretical structure (77, 79, 115).

Building the questionnaire

The Neonatal Satisfaction Survey (NSS) is a structured measure consisting of a number of closed questions. Two response formats were used on a 5-point Likert scale: 1) measuring the level of satisfaction (our overall questions) with the end points of very satisfied to very dissatisfied, and 2) measuring the frequency with the end points of not at all to very large extent. Some of the questions also had “not applicable”, as the 6th point. In line with Garrat et al., the respondents had five pre-coded responses, and we added a comment field to capture comments from the respondents in our validation process (107) to help refine the wording and content (79). To reduce the potential response bias of parents agreeing with a statement (acquiescent response bias), the direction of the wording of questions was varied (115). Most of the questions were worded objectively, as recommended (7, 85), with some positive and negative categories (79). Other items were worded as statements, and there were some questions that directly asked about satisfaction. Questions about facilities were recorded as six choices—very poor, pretty bad, both/and, pretty good, very good and not applicable. The eight categories in the first 42-item survey included three control/overall questions. The

preliminary version of the NSS that was administered in study 1, was based on the PEPC-questionnaire. The first 42-item survey also covered most of the quality indicators recommended by the Norwegian Directorate of Health (116) and was generated from previous literature research (107).

The effect of the order in which the questions appeared in the survey was also taken into consideration. This was taken care of by identifying questions that could be perceived as sensitive and inserting those questions at the end of the survey, knowing that questions triggering emotions can sometimes bias subsequent questions. The sensitive questions were about the health of the child and the parents' experiences of stress. Demographic information was also included at the end of the survey. Questions regarding the extent of overall satisfaction experienced by the parents was included at the start of the survey with questions we consider to be relevant and easy to answer. Space for comments under each category (questions about the doctors, nurses, facilities, etc.) were added so that the participants could note down if there were questions that were difficult to understand or whether clarifications were required for the answers they presented. The first version of the NSS questionnaire was completed in spring 2009.

Expert consultation/interview procedures

In the second version (paper I), we aimed to assure content or face validity and ended up generating more questions after consultations with experts in the field. To strengthen the validity, we wanted to consult both health personnel and parents from NICUs, who represented important competence in the field. First, focus group interviews with health personnel were performed. The intention was to test the first preliminary version of NSS for relevance, clarity and readability and whether there were more questions that would be important to ask from their point of view (77, 79, 112). It was important to receive input from the physicians and the nursing group, as well as the management at the NICU. The focus group consisted of nine health personnel. The second version of the questionnaire (NSS) was completed in autumn 2009.

For the third version of the NSS, ten parents of infants who were previously hospitalized in NICUs were recruited, and a focus group interview was performed. The respondents were recruited from the local organization of heart disease in children and from the premature infant association in Norway. The parents were first asked to complete the questionnaire (NSS) and

then asked to review the questions for relevance, clarity and readability. Second, we wanted them to look at the meaning of the questions, whether questions were or were not understandable or difficult to answer, excessive questions, and if there were more or other questions that would be important for measuring NICU satisfaction. The third version of the NSS questionnaire was completed in spring 2010.

Finally, to validate the fourth version of NSS, a second group of nine health personnel were interviewed. Because the form had changed substantially during the reference group work, the study needed to be newly reviewed by professionals (77); therefore, an interdisciplinary meeting in the form of a focus group interview was performed. The group was asked in advance to comment on the following points: Whether the most important dimensions were covered; help in formulating individual questions; and ethical considerations of what individual questions can signal, potentially generating negative feelings while answering the questionnaire. The most common NICU diagnoses were given as choices in the section asking about demographic data. However, if the parents did not receive a diagnosis, we left an open line for describing their infant's condition. The fourth version of NSS was completed in autumn 2010.

2.1.3 Inclusion and participant flow in the focus groups

To assess views of changes in the way the department operations, the focus group inclusion criteria of parents were that their child was previously admitted to a NICU, and the child was not older than 5 years. The inclusion criterion of the expert health personnel was a minimum of five years of experience in a NICU. There were two focus group interviews with health personnel, with nine people in each group. The first health personnel group helped to validate the first version (developed from the literature), and the second health personnel group helped to validate the third version (from the parent group). The health personnel group included people from the management team, nurses and doctors, and the social worker for the unit. The personnel were recruited from a medium-sized NICU in Norway that held 13 beds and treated infants of all gestation ages, except surgical patients.

2.1.4 Analysis of focus group data

In the qualitative studies using focus group interviews, an interview guide was developed that was suitable for the purpose. The focus groups were videotaped, and all of the content was transcribed and thematically analysed (117, 118). A focus group interview is characterized by

a non-controlling atmosphere, where different perspectives concerning the chosen topic are focused on (119). The purpose of the interviews was to gain insight of the questions that the participants found to be important when measuring parent satisfaction in NICUs. The original video recordings using an iPod were deleted immediately after transferring the material to a secure hospital research server.

The three focus group interviews were marked with group 1 (health personnel 1), group 2 (parents) or group 3 (health personnel 2), along with the date and place of the interview. Each informant was marked with his/her specific number and some anonymous information that could help the project leader identify who said what. The transcriptions were carried out within two weeks after the interviews. The reason for videotaping was that it ensured the quality of the transcription because it was easy to ascertain who said what and in which context, along with nonverbal language that was missing from the audiotapes. Kvale (2007) (120) supports the procedure of videotaping to assess the interactions between the respondents and the interviewer and also to try to identify the emotional tone of the interviews. Every focus group interview was analysed using the same procedure. The transcriptions were carried out word by word in an attempt to recreate the atmosphere of the interviews in retrospect. To increase the validity in the process of analysing the material, a second researcher undertook the same procedure by listening to and reviewing the video recordings.

The first step of the analysis was to get to know the material and to be immersed in the details and achieve a sense of the whole of the interview, and from that the major themes began to emerge (117). Two researchers read the material several times to gain an overview. In this phase, no systematic analysis should be performed (121). The next step of the analysis was to sort the information into meaningful units from the text that appeared to contain knowledge about one or more of the highlighted themes from the first step of the analysis; this helps put the information into context according to the previously developed themes (117, 121). To be systematic, we chose to look for the themes in the semi-structured interview guide. In addition, each question in the preliminary questionnaire was marked together with notifications of the comments from the interviews. Every question from the researcher during the interview was inserted vertically into a table. The number and formulation of the questions from the semi-structured interview guide were plotted into the table when found in the text, with a comment regarding what the informants were questioning, or what they agreed with, about the survey questions.

The third step of the analysis was text condensation. The material was sorted into tables by the themes that were revealed in the first two steps of the analysis (121). To systematically find the meaningful units, each informant's quotes were summarized to generate an overview. This process is termed condensation of meaning, according to Kvale (119). The main research question was to ascertain which survey questions were important to be included in the survey for measuring parent satisfaction in NICUs when their newborn is admitted to a NICU.

After the above analysis was condensed and cut, we summarized the meaningful text, with quotes, into tables with themes from the interview guide. Every piece of text was marked with the page number from the transcripts and with the informant's identification number. The text was interpreted, and two researchers individually interpreted the entire process to increase the internal validity (122). The fourth step of the analysis was contextualization (121) where we summarized the findings of the material. A written summary was created that contained the essence of the focus group interviews.

2.1.5 Pilot study procedures

The draft version of 93 questions was used in the pilot study to harvest the parents' experiences of having their infant hospitalized in the NICU. Parents with infants admitted to a NICU were asked to complete the questionnaire (fourth version of the NSS) and to fill in the comment field, if necessary. The pilot study us to discover flaws within the instrument, examine the reliability and validity of the questionnaire, evaluate how the survey could function in relation to administrative work, and finally, to conduct a factor analysis and reliability test (80). After the pilot study, the fifth version was completed in spring 2012.

2.1.6 Pilot study participants

A total of 105 parents who had their infants admitted to a NICU were requested to answer the fourth version of the NSS questionnaire (pilot test). The parents were recruited from a medium-sized NICU in Norway with 13 beds that treated infants of all gestational ages, except surgical patients. Parents with multiple births received only one questionnaire. Both parents answered each questionnaire, but parents were not excluded if one of them refused to answer. The parents were asked to answer the questionnaire separate from each other to prevent being influenced by each other. The nurses gave the questionnaire to the parents some days before discharge from the unit. During the period of data collection, 161 patients were

admitted. Seventeen were readmitted, and 41 did not meet the eligibility criteria of the infant stay in the NICU \geq two days. One infant was excluded due to a gestation age of < 24 weeks. Parents of 14 patients were ineligible because they did not speak Norwegian, and 29 for administrative reasons. This left 59 patients for the study. Due to single mothers, twins or triplets, the total sample thus consisted of 105 parents. The inclusion period was from the end of September 2011 to the end of March 2012.

2.1.7 Inclusion and participant flow in the pilot study

The inclusion criteria of parents participating in the pilot study were parents ≥ 18 years old with an infant who was admitted to the NICU for more than 2 days, except for cases in which the infant passed away during the stay.

2.1.8 Measures in the pilot study

The fourth version of the NSS questionnaire (93 questions) included questions about overall impressions, experience upon admission and later on in the stay, for themselves and their infant. Questions covered kangaroo care and NIDCAP, interactions between healthcare professionals and parents, external interactions (other units related to NICU) and trust. There were also questions about the siblings, visits, nutrition, nurses, doctors, information, parent anxiety, information about tests and preparation for discharge. Demographic data from the parents and the infant were also included in the survey.

The mothers and fathers answered questions on sociodemographic and medical variables, such as age, level of education, native language, main income, civil status, if they were alone as the caregiver and driving distance from home. Data were also collected on gestation age, the reason of the infant's hospitalization, whether the birth was single or multiple, parents' rating of the health status of the infant during the NICU stay and whether the infant had been previously hospitalized in the department.

2.1.9 Statistical analyses of the pilot study

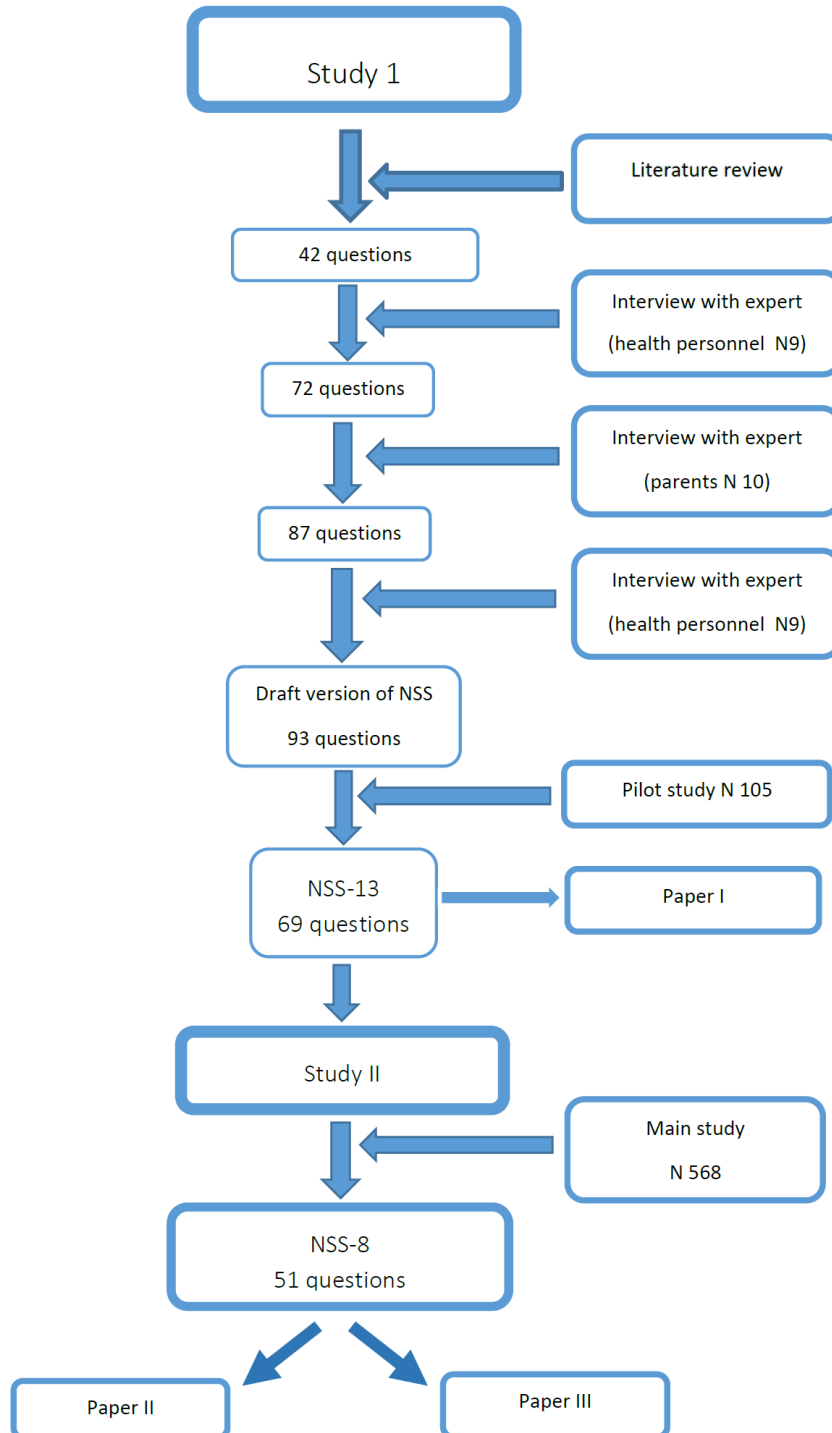
The major aim of this study was to determine the construct validity and the internal consistency reliability of the NSS. Continuous variables were analysed by t-tests. Categorical variables were examined with chi-squared tests. Internal analyses of each category were performed to verify whether the items appeared to measure the same phenomenon. Internal consistency of the scales and subscales was examined with Cronbach's alpha (77). Factor

analysis was used to establish the number of subgroups, examine explained variance, and further validate the patterns in the survey.

All 93 questions were analysed with principal component analysis (PCA). The factor analysis suggested 21 categories. The validation process revealed overlapping questions and questions too detailed for our purposes, along with low factor loading values when examined with exploratory factor analysis. None of the clinically important factors disappeared during the factor analysis. The question of nutrition seemed to be somewhat misleading. The parents chose several alternatives to this question, and it was not possible to differentiate between main nutrition and supplementary nutrition. We changed from separate nutrition answers to satisfaction with different aspects of information, autonomy and knowledge of the different feeding categories. Question about infant nutrition is, to our knowledge, not found in other studies measuring parent satisfaction with NICU care, but we considered this to be important because to be able to feed the infant is often very important for the bonding between parents and infants, especially in regard to breastfeeding. Some questions were omitted due to low factor loadings and because we found that more than 10% of the respondents did not answer these questions. These were questions mainly about the social worker's role in the process, kangaroo care, NIDCAP and external interactions. Finally, some questions about the hospital organization and time out for parents were omitted due to low alpha values, and the explanation of this could be the low number of respondents.

A thorough investigation via PCA suggested loadings that were too low for several items, which were deleted as mentioned above. In the deletion process, we also considered the eventual clinical value of the items. Clinical analysis also suggested that some of the items should be moved to another factor. As reported in paper one, we were aware that the number of respondents was too low to conduct a valid factor analysis. Nevertheless, the two intentions were to verify whether the data were suitable for factor analysis and to test the practical data collection; then we could perform a new study with the strength to properly validate a survey. We tested the reliability of each factor, and they ranged from 0.60-0.89. After re-running the PCA, 24 questions were omitted from the final version, which therefore was termed NSS-13. The fifth version of NSS was conducted using 13 factors as the best solution. This was also in good concordance with our qualitative research. The total variance explained by the 69 items was 84%. Due to the low number of respondents ($N = 105$), we decided to use the results as a direction for the validation process.

2.2 Diagram of the study



2.3 Study 2: The validation and clinical results study, (Papers II and III)

On the basis of the results of the pilot survey, a subsequent cross-sectional study including 568 parents from six NICUs that were geographically spread across Norway was performed.

2.3.1 Design

The study used a cross-sectional and prospective design, with a self-report questionnaire. Quantitative measures were collected from parent responses from the NSS-13 in six NICUs in six different hospitals geographically spread across Norway (paper II).

From the same cross-sectional study, the NSS-8 was used to investigate socio-demographic factors that were associated with parent satisfaction and associations between parent satisfaction and neonatal intensive care services (paper III).

2.3.2 Procedures

First, we had to statistically validate the NSS-13 (paper II). In study 2, we used the same procedure as in our pilot study. Agreements were obtained from six units, each of which would collect at least 100 completed questionnaires. These six NICU units are in a geographically spread area, with a variety of universities and local hospitals. The study was conducted between September 2015 and October 2016. Participating NICUs varied in size from 6 to 21 beds (mean 12.5) and treated between 253 to 500 patients each year. Two NICUs are university hospitals, and the rest have regional or local catchment areas. Three units treat infants with \geq GA 23, and the rest care for newborn infants with GA 26–30. The study was introduced to the nurses in the units, and three research assistants were responsible for the questionnaire distribution and collection. The research protocol to be followed was distributed to all unit nurses and was placed in a prominent position within each unit's nurses' station. During the data collection phase, the leader of the project had regular contact with the research assistants by telephone and email. Some units were also visited during the collection phase.

As discharge approached, the research assistant contacted the infant's next of kin to secure their informed consent to take part in this study. The research assistant left a copy of the self-report NSS-13 questionnaire with the parents who had agreed to take part. The parents answered each questionnaire. Parents with multiple births received only one questionnaire. Confidentiality arrangements were explained, as was the protocol, emphasizing that no completed questionnaires would be read by anyone working at the unit. The participants took approximately 30 minutes to complete the survey. The respondents provided demographic

information about themselves and their infant. To avoid sampling errors, we carried out an attrition analysis for each hospital because of the inclusion criteria.

2.3.3 Participants

In study 2, 568 parents were included in the survey, consisting of 312 (54%) mothers and 256 (45%) fathers. The same procedures as in the pilot study (study 1) were used, and the response rate from the six hospitals participating in the study varied from 33 to 66%, with a mean of 45%. This study was conducted between September 2015 and October 2016.

2.3.4 Inclusion criteria

Inclusion criteria were Norwegian- or English-speaking parents admitted to one of the six NICUs whose stay had lasted for more than two days, except for cases in which the infant passed away during their stay.

2.3.5 Measures

In paper II, we used the Neonatal Satisfaction Survey (NSS-13), which is the fifth version and contains 69 items derived from 13 categories or themes relevant to parent satisfaction with the care provided in NICUs. The themes included the following: Staff, Admission, Nursing Personnel, Anxiety, Siblings and Other Next of Kin, Information, Time Out, Doctors, Facilities, Nutrition, Preparation for Discharge, Trust, and Visitors. Cronbach's alpha varied between 0.60 and 0.89 for the thirteen factors. The same demographic variables as in paper I were used, and two questions about parents' social support from friends and families were added. An English language version of the NSS-13 was developed by translating to English and then back to Norwegian by professional translators (appendix 2). In this study, a comment field was not used because we wanted to only statistically validate the questionnaire.

In paper III, after statistically validating the NSS-13, the sixth version (now named NSS-8) contained eight factors, which were extracted based on a principle component analysis of the 568 respondents (123). These factors covered aspects related to *care and treatment*, *doctors*, *visits*, *NICU facility*, *siblings*, *information*, *parent anxiety*, and *discharge*. Cronbach's alpha varied between 0.70 and 0.94 for the eight factors. The various questionnaire items were measured by a Likert scale with 5 to 6 alternatives. The questionnaire covered FCC principles (31, 32, 36, 109) and was used to gauge parental satisfaction with the services provided within the NICUs. Further validation was completed, and the questionnaire was found to be suitable for measuring the parents' overall satisfaction and their experiences in the eight spheres of care.

2.3.6 Statistical analysis

In paper II, descriptive statistics were first conducted. All items used in the survey were first analysed by the descriptive information given. Demographic differences between the mother and father were analysed with the Pearson chi-squared test, (p value set to ≤ 0.05).

Correlations were tested by using Spearman's rho. All significant tests were two-tailed.

A factor analysis for data reduction was conducted, and the factor extraction was based on the principal component method using the total variance of all variables. The factor solution used the orthogonal rotation method Varimax (124, 125). To assess the appropriateness of the factor analysis regarding sampling adequacy (high level of multicollinearity), the Kaiser-Meyer-Olkin (KMO) statistic and Bartlett's test of sphericity were used. The KMO value varies from 0 to 1 and predicts the likelihood of the data to factor well based on correlations and partial correlations. The KMO should be larger than 0.5 (124). Bartlett's test of sphericity tests the null hypothesis that the intercorrelation matrix stems from a population in which the variables have no correlations. The factor loading of variables on a particular factor indicates the correlation between the variable and the factor, and it should be higher than 0.3 to contribute to the overall KMO. Variables with factor loadings below 0.3 were eliminated (124).

Two of the 69 questions from the NSS-13 were omitted prior to factor analysis because of the overall character of the questions. The exploratory factor analysis with Varimax rotation was performed with 67 questions that were related to the satisfaction with care in the NICU and were included in the factor analysis to remove questions that were not performing well (factor-loading-wise). The correlation matrix was used to screen and reveal questions that were too highly correlated (> 0.9 , zero questions) or did not significantly correlate with other questions (15 items). These were mainly the questions referring to the child's nutrition, questions related to the parents' perceptions of the child's pain, stress, and waiting time, and the parents' need for a break from the unit. The Kaiser-Meyer-Olkin (KMO) and Bartlett's tests showed that the data were acceptable for factor analysis (KMO index = 0.918, $\chi^2 = 5279.759$, $df = 2211$, $P < 0.000$). The rotation sums of squared loadings provided 16 factors explaining 56% of the variance, but the scree plot indicated the possibility of using eight factors. When using the Kaiser criterion, it was found that too many components were extracted. It is therefore important to also look at the scree plot to spot changes in the shape of the plot (86).

Initially, 12 of the 15 questions were removed because they did not significantly correlate with other questions. All six questions about nutrition were omitted from the factor analysis, along with two questions containing staff caring about the infant's stress and pain, unexpected waits (latency) in the unit, personnel communicating hope, children given the wrong treatment, and the parent's need for follow-up regarding their own reactions. The three other questions regarding two items related to whether the parents were offered or needed a break from the NICU and information about the result of tests seem to be too clinically important to be removed at this stage.

We ran the EFA again, and the total variance explained 56.30% of the variance with 12 factors in 55 questions. The rotated factor matrix shows the questions loading on the 12 factors above 0.3. Factor 9 carries only two questions. Ideally, we would like three or more questions loading on each factor, but we decided to keep these two questions due to clinical interest. The questions were whether the parents were offered or needed a break from the NICU. Factor 10 also carried only two questions. The first question was whether there was one doctor caring for the child, and the second question was whether a permanent group of caregivers cared for the child. The two questions loading on factor 11 and 12 load much more on factor 1. Finally, one question regarding the siblings' reactions and one regarding information about lab tests did not load on any of the factors. We decided to omit the two questions not loading on any factors and the two in factor 9. After forcing an eight-factor solution, we found that the two questions we wanted to keep because of clinical interest showed acceptable loadings on factor 1 and factor 2. Finally, eight factors with 51 questions were extracted by using the Kaiser criterion and rotated factors (Eigenvalue >1).

To establish questionnaire reliability (repeatability, stability and internal consistency), Cronbach's alpha, average variance extracted, and inter-subscale correlations were calculated. The reliability/convergent validity of the final version of the NSS was confirmed. The total alpha of all 51 questions was 0.949. Pallant (2010) recommends looking at alpha if an item is deleted, and if any of the values in this column are higher than the final alpha value, you may consider removing the item (86). None of the values were higher than the final alpha; therefore, it was not necessary to omit any questions. The standardized factor loadings of the items within the factors from the rotated factor matrix were as follows: Care and Treatment, 0.709-0.325; Doctors, 0.800-0.325; Visit, 0.806-0.679; Information, 0.713-0.387; Facility, 0.646-0.470; Parent Anxiety, 0.849-0.510; Siblings, 0.818-0.588; and Discharge, 0.635-0.502.

The items used for the factor modelling are originally measured on a scale of 1-5. To present the results of the different factors in percentage rates, they have been transformed to a 0-100 scale.

In paper III, the internal consistency of NSS-8 had already been analysed (paper II). Descriptive statistics were analysed with the Pearson chi-squared test (p value set to ≤ 0.05), including frequencies and percentages, and these are shown for all eight NSS-8 factors and the socio-demographic variables. Continuous data were transformed into categorical data and presented in the descriptive statistics. Because the data were strongly skewed (towards high satisfaction), nonparametric methods were used to compare the overall satisfaction scores with the demographics, support, and single items in NSS-8. Chi-squared tests were used for associations between variables. The relationship among the eight factors of perceived satisfaction with care, demographic data, and support was investigated using Spearman's correlation coefficient.

The variables in NSS-8 were dichotomized according to clinical decisions. The cutoff on the five-point Likert scale was set between those scoring "not at all", "small degree", and "some degree" of satisfaction (low satisfaction) and those scoring "largely" and "very large extent" (high satisfaction). The NSS-8 measures the degree of parental satisfaction with NICU health services, but the category *parental anxiety* measures the degree in which parents worry for their child. The two overall questions, *satisfaction with infant treatment* and *satisfaction with parent treatment*, were dichotomized as follows: items 1–3 (very dissatisfied, quite dissatisfied, and neither satisfied or dissatisfied) were classified as "low satisfaction"; and items 4–5 (quite satisfied and very satisfied) were classified as "high satisfaction". These two variables and selected dichotomized variables from the NSS-8 questionnaire were then cross tabulated. Direct logistic regression was performed to assess the association between socio-demographic variables and support and the likelihood that respondents would report satisfaction with care. The dependent variable was a dichotomized version of the average of the 51 questions dealing with the various aspects of satisfaction, where (after clinical assessment) values from 1 to 4.1961 (the median value) were labelled as "low satisfaction", and values higher than 4.1961 were labelled as "high satisfaction".

The skewness in questionnaire responses is markedly towards parents who are satisfied with NICUs. Aspects of services to be improved are difficult to establish by statistical means. Therefore, we decided to describe the areas where more than 10% (cutoff: $N \geq 14$) of the respondents reported dissatisfaction with the NICU, given that they also reported dissatisfaction of the stay in the NICU in the overall question. The cutoff for the number of respondents was set based on our assumption that 10% of the respondents could have given their answer by coincidence and with a desire to refrain from overanalysing dissatisfaction report in such a skewed material. A two-tailed p-value of less than 0.05 was considered to be statistically significant.

2.4 Ethics

The respondents were parents to a child with a minimum gestation age of 24 weeks, and answering a large survey could possibly be regarded as a burden. Participating in the survey might in itself add worries to the parents. On the other hand, it is also likely that the parents felt empowered by answering the questions and being able to state their opinions. Due to ethical considerations, we emphasized the voluntariness of participating in the study and of their right to withdraw from the study. We also emphasized that their participation or non-participation would not influence the treatment in the NICU. Due to the assumed vulnerability of the parents, we decided to carry out the interviews a few days prior to discharge and not in the initial crisis period. Since the parents were admitted to the hospital together with their child, health personnel were close by in case some of the questions of the NSS triggered emotions that were difficult to handle. In addition, they were given the researchers contact information. The study was presented to the Regional Ethical Committee in Norway. They responded that as long as we interviewed the parents, the study was outside of their mandate. Nevertheless, we treated the parents as a vulnerable group, which we consider them to be during this difficult time. All of the respondents gave informed oral and informed written consent to participate after having read an information letter concerning the study.

3.0 SUMMARY OF RESULTS

3.1 Paper I (Study 1) Development and validation of Neonatal Satisfaction Survey-NSS-13. Hagen, Inger Hilde; Vadset, Tove B.; Barstad, Johan; Svindseth, Marit Følsvik. (2015)

To develop the Neonatal Satisfaction Survey, a structured process was followed. The literature review supplied important information on relevant topics to be included in our survey. These topics were nurses' and doctors' ability to show empathy, respect, and caring for the child; the availability of health personnel when parents needed to talk; the clinical competence of the health personnel to provide parents with information and to listen to them in decision-making; and the physical environment (65, 111, 112, 126). The first step consisted of 25 items from Garrat et al. (107) and 17 questions from the literature review, for a total of 42 items. The expert focus group supported the first step and added their views and new items in the areas of the child's nutrition, available information, and visitors' utilities. Thirty questions were added accordingly. Parents who experienced having their children admitted to a NICU evaluated the second version of the NSS. The parents had opinions on the importance of feeling safe in the demanding situation of having a child admitted to a NICU. They also suggested questions on how health personnel could help parents to cope. At this stage, 15 new questions were added. The third step of the survey was conducted with a new round of expert health personnel, and they suggested the rephrasing of some questions and additional topics, such as caring for the child and the anxiety of parents. After analysing the third focus group interview, the fourth version contained 93 questions. The main comment from the second expert group was that the survey seemed to cover all relevant topics. Finally, common factor analysis resulted in 69 questions on 13 factors and explained 84% of the variance. Cronbach's alpha varied from 0.60 to 0.89. A total of 24 items were omitted from the final version of the NSS-13. Not many parents left a comment in the comment field of the questionnaire. Those who did comment left advise on how to improve the care, or for example, stated that they were very satisfied with primary care, but were not satisfied with the weekend care.

3.2 Paper II (study 2)

Validation of the Neonatal Satisfaction Survey (NSS-8) in six Norwegian neonatal intensive care units: a quantitative cross-sectional study. Hagen, Inger Hilde; Svindseth, Marit Følsvik; Nasset, Erik; Orner, Roderick; Iversen, Valentina Cabral. (2018)

To perform a proper validation of the questionnaire, it was necessary to do a larger survey; therefore, study II was conducted. The study included the NSS-13 questionnaire returns from 568 parents, and the final questionnaire ended up with 51 items in eight factors, explaining 53.27% of the scale's variance. The correlations between questions were acceptable (KMO = 0.938, Bartlett's test of sphericity gave $\chi^2 = 4813.142$, with $df = 1275$, and the significant level of the null hypothesis was far below 0.05 ($P < 0.0001$).

The value of Cronbach's alpha was greater than 0.7 for all the items, and the inter-subscale correlation was between 0.70 and 0.94. The average variance extracted (AVE) values for the eight factors were mostly above the recommended level of 0.50. The only exception was the *Care and treatment* factor showing an AVE of 0.464. Discriminant validity was present for all the eight factors, as the AVE's were larger than any of the squared correlations between pairs of factors (127). The total alpha of all 51 questions was 0.949. In the corrected item total correlation, the items correlated between 0.362 and 0.718, except for three items concerning questions about the parents' worries about their child not surviving and after-effects, as well as one item regarding facilities (0.115, 0.136, 0.284). We did not omit these questions because we considered these items to be of clinical importance when measuring the quality of healthcare in NICUs.

Convergent validity was explored by examining the relationship between the NSS scale and the questions measuring overall satisfaction with care by using Spearman's rank correlations. Correlations between the 8 factors in the questionnaire and the two global questions of satisfaction provided support for the convergent validity of the questionnaire.

Parent satisfaction rates were measured, and the highest satisfaction rate was on factor 1 "Care and Treatment", with a score of 86%, and this included 22 items. The lowest rate was on factor 8 "Siblings", with a score of 64%.

3.3 Paper III (study 2)

Parental Satisfaction with Neonatal Intensive Care Units: A quantitative cross-sectional study. Hagen, Inger Hilde; Iversen, Valentina Cabral; Nettet, Erik; Orner, Roderick; Marit Følsvik Svindseth. F. (Accepted 22.12.18)

We compared sociodemographic data with satisfaction with NICU care. Receiving support from family and friends and infant health are the factors most important for the level of satisfaction. Support from family and friends generates significantly positive correlations with all factors, except for the siblings factor. Higher levels of support increase the satisfaction level and decrease parent anxiety. Infant health is significantly and negatively correlated with all eight factors, indicating that better infant health leads to greater satisfaction with the NICU and less parental anxiety. The logistic model that includes thirteen independent sociodemographic variables shows that that parent's age, education level, support from friends and family, infant health and infant GA made a unique statistically significant contribution to the model.

Most of the parents (76%) reported moderate to high levels of satisfaction with NICU care. To investigate what parents are most and least satisfied with regarding NICU services we conducted a chi-squared test using the 51 questions in NSS-8 and the 2 overall satisfaction questions. Parents who had one doctor with the principal responsibility for the child were significantly more satisfied with the NICU than those not experiencing such continuity. The same was found for parents reporting a permanent group of caregivers caring for the infant compared to those who did not experience continuous support. Those reporting that care personnel had time for the parents and parents receiving continuity of care were also significantly more satisfied with the NICU. Similarly, perceived respect and understanding from the health personnel led to significantly increased levels of satisfaction. We found significant associations between parents reporting perceived consideration and care from nurses and doctors and satisfaction with care. We also found significantly positive associations between satisfaction and having health personnel who were interested in listening to parents' opinions on the care and treatment of the infant. For those 24% of parents who reported dissatisfaction, most were dissatisfied with how NICUs are prepared for the siblings of the infant. Improvements are also needed in following areas: continuity of care, information, and follow-up.

4.0 DISCUSSION

The principal aim of this thesis was to develop and validate an instrument to measure the satisfaction with NICUs from the important viewpoint of the next of kin. Currently, there is a lack of validated questionnaires for the purpose of measure parent satisfaction in NICUs.

4.1 A new instrument in Norway measuring parent satisfaction in NICU

In paper I, we focused on topics related to NICU parents and their infant age group and covered FCC principles (40, 107, 108), which strengthened the thesis because researchers have previously requested a questionnaire covering FCC principles (35). Questions regarding family involvement, such as the infant's siblings and visitors, in addition to parental anxiety, are also important aspects to cover (37, 128) and are in many ways related to FCC principles. To our knowledge, one other study that has reported validity and reliability, has covered all FCC principles (the EMPATHIC-N) (68), as stated by a previous review (36), but we did not find that the instrument covered the items of siblings and visitors. Facilities for siblings and visitors are important when working to involve the family in care and treatment. In the new Norwegian national professional guidelines for competence and quality in newborn intensive units, it states that "If the infant has a sibling, NICUs facilitate the siblings visit to the newborn" (128 p39). Questionnaires that address these factors, except for the NSS-8, have not been found. The literature highlights the importance to facilitate the parent's needs, and in this context, only one instrument has addressed facilities for the parents (NPSQ) (72). However, this questionnaire does not cover all FCC principles. According to the European Association for Children in Hospital charter, "children in hospital shall have the right to have their parents or parent substitute with them at all times" (129 p.8). The bonding and attachment process is based on the close proximity between infant and mother and the mother's adapted reactions to her newborn's cues (130). In this context, proper facilities are an important factor for parents living in the unit for several days and weeks. It is also important to measure parental anxiety, worries and stress and to improve service by facilitating the parents' needs to improve their quality of life while the infant is hospitalized in the NICU. We found just one questionnaire covering questions about parental anxiety (76), but the study did not report reliability and validity. The pilot study resulted in the NSS-13, which consisted of 67 questions covering 13 factors or themes.

4.2 The suitability of NSS-8

In paper two, after the validating process of NSS-13, the questionnaire was reduced to eight factors (NSS-8) with 51 specific questions and two overall questions. The main findings were that NSS-8 is a suitable instrument to measure parent satisfaction with NICUs. A statistical analysis showed that the NSS-8 is valid for its purpose, and the results indicate that the NSS-8 has optimal quality. It is not easy to compare the NSS-8 with other instruments of interest, given the aim of the instruments and the different populations. Only three validated parent satisfaction instruments have been documented in the literature for the NICU setting (68, 71, 72). The instrument developed in the UK (P-BESS) was assessed for validity and reliability (71). Despite the proper testing of the 17-item questionnaire, the authors stated that one limitation of the instrument is a low response rate (30%), and the sample size was relatively small for factor analysis, which limits the validation process. The questionnaire also included only parents to very preterm infants, not all parents in the NICU. The second instrument from Iran (NPSQ) was developed for an Iranian cultural context (72). The instrument aimed to cover development care principles, including items such as reduction of noise and light and providing an environment similar to intrauterine conditions, which are not FCC principles. The only instrument that can be appropriately compared to NSS-8 is EMPATHIC-N from The Netherlands (68). This instrument has 57 statements within five domains and covers FCC principles. A limitation of the validation process for EMPATHIC-N could be that the researchers collected data from only one unit, and the sample size of 220 parents answering 67 questions could be at the lower limit for construct validity (124). In contrast, the NSS-13 questionnaire used 568 parents and 67 questions, which is a very good sample size for factor analysis (124, 131). The EMPATHIC-N (68) did not separate questions or statements about doctors and nurses or address facilities for parents and facilities for siblings, as recommended in the Scandinavian guidelines for quality indicators of patient satisfaction in hospitals (90, 116, 128). Because nurses are found to be the most important care providers in hospitals, there should be an emphasis on nursing service quality as one of the determining factors of parent satisfaction (132, 133). Other studies have found a significant relationship between the satisfaction with hospital stay and nursing courtesy, respect, careful listening, easy access of care, work environment, and patient-nurse staffing ratio (134-139). NSS-8 contains questions regarding most of these items (appendix 1).

The strength of the NSS-8 lies in the content validity, where the question selection was developed by consulting both the parents and the healthcare professionals, as recommended in

the literature when developing tools for quality assessment (97-99). The NSS-8 also addresses most of the FCC concepts (9, 30, 31) and recommendations and guidelines from the Norwegian and Scandinavian authorities (90, 116, 128). It is, therefore, recognized that the 51 questions divided in eight factors reflect the most important issues of the NICU care. It has been suggested that satisfaction is a necessary, but not sufficient condition of effective care, and that the key to evaluating the quality of care is a mix of clinical- and patient-centred outcome measures (7). The Norwegian Directorate of Health has released National Professional Guidelines for Newborns and confirms that quality indicators are needed to measure and further develop guidelines for good treatment. In anticipation of national quality indicators, they refer to the Danish quality database for newborns, which has nine registered quality indicators. These include, among other things, survival, frequency of breastfeeding, kangaroo-mother care, growth and pain scores (128). Quality or satisfaction with the NICU, seen from the parent and user perspective, is not mentioned. The Norwegian Directorate of Health also recommends indicators for quality when measuring patient experiences and satisfaction with the healthcare in general hospitals (116). In this PhD thesis, those factors were included when developing the NSS-8, and we therefore consider the instrument to be an important supplement in the quality measurement of NICUs (attachment 1). Satisfaction surveys might not be the gold standard for measuring quality, but instead form part of a wider evaluation system. Other approaches, such as discharge meetings with the parents, parents' meeting the health personnel in focus groups, or follow-up (telephone) interviews after discharge could be a better method to measure satisfaction with the healthcare received, but those methods are resource intensive. The challenge is also to capture not only quantitative measures but also qualitative findings, for example by providing space for written comments.

The exploration of the parents' narratives in satisfaction surveys might provide valuable in-depth meaning of the quantitative measures (140, 141). Analysing the combination of both types of measures has benefited quality improvement projects (126, 142). The NSS-8 also provides space for comments. Therefore, questionnaires such as the NSS-8 could be a suitable instrument to use when trying to reach a wider number of parents. However, the importance of validated satisfaction instruments stretches beyond the evaluation of care only. In scientific research, satisfaction with care has been proven to be a valuable outcome measure for family and parental support interventions (133, 143). Therefore, the NSS-8 cannot only be used to assess the experiences and satisfaction with care, but can also be used as a primary outcome measure in future interventional studies.

4.3 Characteristics of factors that parents were satisfied

In paper III, we found that most parents reported moderate to high levels of satisfaction (76%). High satisfaction levels have also been observed internationally (66, 101, 144) and in other healthcare units across Norway and in comparable countries (132, 145). In addition, the parent gender, education level and age were found in some studies to have impact on satisfaction (101-103). In the present thesis, the most important factor for reporting a high degree of satisfaction with the NICU was social support from family and friends. This factor has not, to our knowledge, been explored in any prior research and is an important factor for healthcare personnel to consider when giving care to the parents in NICUs. When an infant is premature or sick and admitted to a hospital, the entire family is affected. In providing care, nurses, doctors, and others who provide care for the child must consider the impact of the infant's being admitted to the hospital on all of the members of the family. It is, therefore, important that healthcare professionals be considerate of parents who live either far from the NICU, travel from another country or, for other reasons, do not have frequent contact with their family, to enable the family to have contact in the NICU.

Parent satisfaction with the healthcare they received was also measured. The most important factors for parent satisfaction with NICU services were involvement in decision making regarding the infant, respect and empathy from staff, and continuity of care and treatment. In the present study, we found that the relationship between health personnel and parents is an important factor for parental satisfaction with the NICU. We found significantly higher satisfaction among those parents who reported that one doctor had responsibility for the child, that they had one permanent group of caregivers, and when healthcare personnel had time for the parents and conveyed respect and understanding. Other studies have noted the relationship between patient and practitioner as the most important health service factor affecting patient satisfaction (7, 10, 50, 146-150). This relationship emerges as a key factor in parent satisfaction with care in the NICU (48, 49, 144). The FCC statements also highlight this relationship as important when caring for infants in hospitals (109). Using the NSS-8, healthcare personnel will be able to monitor how well the unit accommodates the parents according to those factors.

Approximately one-fourth of the parents in our study showed moderate to low satisfaction. However, room for improvement may be found even when a service is regarded as good or excellent. The questionnaire responses reflected a high level of parents perceived quality for

the full range of NICU services, and as such sets a baseline to aspire to. The study revealed some specific areas on which healthcare personnel should focus. The worst performance was supporting the infants' siblings, which is an integral part of assuring high-quality services under the FCC approach in NICUs. Unfortunately, and despite the efforts made to support siblings, there are too few studies on sibling support and comprehensive services (151). The present study, along with other studies (49, 144, 148), demonstrates that parents need healthcare personnel to provide consideration, information, and continuity of care during the entire period in the NICU. These findings convey that healthcare professionals have an opportunity to increase parental satisfaction in the NICU and help to improve outcomes.

Other validated instruments have been used to document parental experiences and staff support to parents, such as the NICU Family Needs Inventory and the parental stress scale NICU (44, 74, 75). However, the concept of satisfaction is not synonymous with the assessment of stress and needs. Having met the needs of parents does not guarantee satisfaction; therefore, the NSS-8 presents a comprehensive parent satisfaction questionnaire, measuring a wide range of today's important NICU care practices. The NSS-8 has been proven to be reliable and valid, with an adequate empirical structure of the questions covering the eight most important factors.

4.4 General discussion

Community policies and legislation, as well as professions that provide services to patients and clients are involved in influencing health care and the services that are offered in the organization. Essentially, in a debate on quality in the health service, one question is how patients and users are perceived. Empowerment is identified as important in healthcare. The philosophy of FCC, which presents parents as consumers of healthcare, has changed the priority in healthcare from a belief in beneficence to autonomy and has led to parent views being taken into account during medical decision-making. Over the past 30 years, measuring patient satisfaction has increased in popularity in line with changes in healthcare. Looking back in time in the neonatal intensive care unit, we see that the perception of giving good neonatal care has changed along with social development in general. In the healthcare system, over the past 50 years, a highly paternalistically controlled system has now been centred around the patient and family. Who judges what good health services are is not only left to the professionals in the field but also to the users. It is the parents of children in NICUs who will receive the services, for themselves and the infant. Therefore, the parents will have to set the

premises for how to measure quality from their point of view. They will be important contributors to the culture of what health services offer.

Parent satisfaction is a multidimensional concept consisting of various aspects that do not necessarily have to do with the actual quality of care and service experienced by the parents. Each family is unique in terms of its structure, cultural context, aims, policies, and its informational, support, and service needs. However, early assessed satisfaction may be influenced by expectations (3, 88, 89). In NICUs, many mothers have given birth unexpectedly to a premature infant, and this could have a negative impact on satisfaction ratings (11). It may also be difficult to distinguish between satisfaction with the childbirth experience and satisfaction with the care received. There are reported factors, such as a long or short perinatal stay, instrumental operative delivery, unexpected medical problems, multiple physical symptoms, and complicated perinatal courses, that need to be related to dissatisfaction (152). The timing of administering a satisfaction questionnaire is important because it might influence the response rate and the answers given. When an infant is hospitalized in a NICU, the parents often experience stress and worries. Before discharge from a NICU, most parents have become accepting of their life situation and experience, are familiar with the NICU and are coping with parenting in this setting, which could increase satisfaction. When parents and infants move home, a new life is starting, and one can experience more stress and uncertainty at first, which may change the perception of satisfaction.

One can argue that expressed satisfaction may reflect user expectations, experiences and knowledge, rather than the quality of the service and care provided. When surveys measure expectations and personal opinions in contrast to measuring what actually happened, it is difficult to decide what can be done better to increase both quality and user satisfaction. If users have low or unclear expectations of service quality and a limited knowledge of opportunities, they may record high satisfaction even if poor standards of care have been provided (7). One might think that this may be the case for parents with infants in NICUs because this specialized unit is often unknown to most people; therefore, the parents often do not have many pre-defined expectations.

4.5 Limitations and strengths of methodological choices

Some limitations of the psychometric testing need to be addressed: First, convergent/concurrent and discriminant validity and predicting how well the questionnaire correlates to another validated instrument, i.e., the gold standard, was not tested. Few validated parent satisfaction instruments are available; the questionnaire that might be the most comparable is EMPATHIC-N (68). Additionally, many of the questions in NSS-8 were not present in EMPATHIC-N. However, there is no definitive standard for measuring satisfaction in any previous study. In our survey, before the pilot study (67), we included validated questions from the Garrat et al. survey (107), which also included the Norwegian government's recommendations for indicators of healthcare quality in hospitals (153). In respect of the available instrument, convergent validity was chosen to test the NSS-8 questionnaire on two generally accepted overall satisfaction questions.

A second limitation is that the test-retest reliability among the same group of parents at two different time points was not performed. The test-retest reliability is of particular importance if the intended use of the measure is to assess changes over time or when current mood states are not likely to remain stable over a period of a few weeks. In this case, we know that recall bias will influence parents' memories and experiences of satisfaction, and this can change when the parents return home and start their new lives. However, we did not want to burden parents with two questionnaires in a short time period due to the experienced stress and anxiety of a NICU admission of their infant (15, 21).

The parents in our study answered the questionnaire while still in the NICU, and they reported a high overall satisfaction with their stay. Parents may have felt reluctant to criticize the professionals who had taken care of them and their infant, which might have contributed to a bias in the questionnaire returns. A longitudinal approach may have been better. Additionally, measuring expectations and satisfaction some time after discharge could have provided a better insight into this phenomenon. Health outcome is also a predictive factor for satisfaction with healthcare (7). In this study (paper III), 94% of the parents ranked the infant's health as good, which could increase the satisfaction rate.

In our study, the respondents represent 45% of the population, which is a large number of respondents from a wide geographical area in Norway and is higher than average for Norwegian national patient-experience surveys (132). This response rate provides statistical

power and protection from bias. To protect from selection bias, we tested possible differences between the responding and non-responding groups and found no differences in GA and length of stay. However, we cannot predict how the non-responding group would have answered the survey.

The reason why 55% of the parents did not answer the NSS-8 could be due to a lack of data from refugees who did not speak any of the Scandinavian languages nor were conversant in English. This lack of data was a feature of the survey period, during which parents from Syria formed a notable group. Additionally, a number of responses were not collected due to administrative errors.

The strength of this study lies in the rigorous development of the satisfaction instrument, which followed a structured process that was recommended by the questionnaire development literature (77-80). To strengthen the validation process, three rounds of focus group interviews to cover face and content validity was conducted. Content validity (or face validity) refers to expert opinion concerning whether the scale items represent the proposed domains of concepts the questionnaire is trying to measure. Next, a pilot study was performed to pre-validate the questionnaire and give us additional direction for the main study. Pre-testing and pilot testing minimize the chance that respondents will misinterpret questions and fail to recall what is requested or misrepresent their true responses and were used to improve the survey.

Psychometric testing of the NSS-8 questionnaire revealed that this instrument is reliable and valid for measuring parent satisfaction of neonatal intensive care services. The 51 items representing eight factors provide a comprehensive conceptualization of parent satisfaction. This survey is based on both mothers and fathers, and many fathers participated in the study (45%). The high participation of fathers is a strength because studies suggest that the fathers' experiences with care in the NICU differ from those of the mothers (154) and could therefore influence fathers' evaluation of care. Fathers of sick, preterm babies are recognized as a difficult group to recruit for research (155).

5.0 CONCLUSION AND IMPLICATIONS FOR PRACTICE

This thesis developed and validated a survey to measure parent satisfaction in NICUs and provides new knowledge relevant to parent experiences and satisfaction with neonatal intensive care units (NICUs). Despite the recognition that satisfaction outcome measures are increasingly used as important indicators to improve healthcare services and provide quality with care (15, 133, 156), the importance of validated satisfaction instruments stretches beyond the evaluation of care only. In scientific research, satisfaction with care has been proven to be a valuable outcome measure for family and parental support interventions (133, 143). Therefore, it was important to develop and validate the NSS-8 for use worldwide. With NSS-8, the NICU services have a tool that sheds light on important questions that have not been previously addressed. The questionnaire is grounded in principles identified as important measurements by the WHO, OECD, and policies and legislation both in Norway and other comparable countries and follows FCC principles. This questionnaire will contribute to improving NICU care and quality in the units, seen from the parents' viewpoint.

Various issues concerning the use of parent satisfaction measures should be addressed. First, NSS-8 can be used to monitor standards in NICUs as seen from the parents' viewpoint and to identify and test necessary improvement projects. Second, the instrument may be practically used in NICUs to ensure that the department maintains standards within FCC principles. Third, the validated satisfaction questionnaire can be used for benchmarking among NICUs and might be widely applicable in many countries. The instrument can be used in full, or its individual categories can be used to monitor satisfaction with the different areas in NICUs and parental satisfaction with different categories. One can investigate similarities and differences between units within a country or compare NICUs with other countries. NSS-8 is easy to use and has been validated and proven to work well in practical use to document clinical practice. The questionnaire is easily customized for statistical analysis and software applications. In addition to parent feedback to improve the quality of care, satisfaction surveys used over time are important to monitor and evaluate the implemented changes. Currently, there is only one developed and validated questionnaire that measures parent satisfaction with NICUs that covers FCC principles in different stages of the care delivery process in Scandinavian countries—the NSS-8 from this PhD thesis.

6.0 FURTHER DIRECTIONS

The task of discovering parents' experiences and satisfaction with NICU care has not come to an end. This thesis explored parent satisfaction within six hospitals geographically spread across Norway. The following areas deserve priority:

- Explore parent satisfaction in all Norwegian NICUs;
- Validate the NSS-8 in other countries/cultures;
- Investigate the characteristics of non-responders and their experiences of care;
- Explore the influences of family culture and context on perceptions of care;
- Explore the differences and similarities between father's and mother's satisfaction with care;
- Explore the relationship among parental stress, anxiety and depression on satisfaction with the received healthcare.

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Paper I

Development and validation of Neonatal Satisfaction Survey – NSS-13

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Development and validation of Neonatal Satisfaction Survey – 13

Aims: The purpose of this study was to develop and validate a survey to investigate parents' satisfaction with neonatal wards in a population of parents of children with a gestation age of ≥ 24 weeks to 3 months after full-term birth.

Method: We explored the literature and conducted three focus groups: two with expert health personnel and one with parents. We tested the survey in a parent population (N = 105) and report the different stages in the validation process along with the full survey, the Neonatal Satisfaction Survey – 13 categories (NSS-13).

Results: We found 13 subcategories in the Neonatal Satisfaction Survey. The subcategories measure parents' satisfaction with neonatal units based on staff, admission,

nurses, anxiety, siblings (parents' perceptions of caring for the siblings of the newborn), information, timeout, doctors, facilities, nutrition, preparation for discharge, trust and visitors. Each subcategory showed acceptable internal consistency. The full version of the Neonatal Satisfaction Survey presents 69 items, and each subcategory contains two to eleven items.

Conclusion: The Neonatal Satisfaction Survey seems suitable to measure parents' satisfaction with neonatal units and can be used in full, but it can also measure subcategories. Parents' satisfaction with neonatal units can be used to improve the quality in such wards. We consider this study as the first in a series to validate the NSS-13. The full survey with subcategories is presented in this paper.

Keywords: development, validation, neonatal, newborn, parents, questionnaire, survey, satisfaction.

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Introduction

It is widely accepted that parents' perspectives and those of next of kin are important when measuring the quality of health care (1, 2). International studies demonstrate significant associations between parents' satisfaction with health care and the parents' abilities to care properly for their child (3, 4). Garrat et al. (5) have shown that a higher level of satisfaction with health care will yield better treatment compliance, due to the important role of parents in the treatment process. Most of those with a sick newborn or premature child suffer a traumatic event. Different negative experiences in the hospital will add to the trauma and reduce the effectiveness of coping mechanisms (6). Studies point to the associations between having a child in a neonatal intensive care unit (NICU) and development of

post-traumatic stress disease (PTSD) and grief in parents (7–11). Having a premature child may also affect the mother–child relationship in a negative manner and can lead to problems in attachment even if the final outcome is considered successful (11, 12). If professionals are able to encourage and support the fathers, they may, in turn, support their partners' transition to motherhood as the fathers prioritise their partners' needs (13).

It is of utmost importance that the specialised NICUs are inclusive of parents and that health personnel are highly qualified technically and clinically as well as competent to take care of parents and address their reactions (6, 14). Norwegian national guidelines give directions on how health personnel can contribute to supporting parents to be the best possible caregivers for their children in such traumatic circumstances. The parents are given legislative rights to be with their child as much as possible, to be provided with information on health status and to take part in decision-making about their child's health care (6, 14).

A few instruments have been developed to measure parents' satisfaction with different healthcare systems (4,

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5, 15–21), but we consider them unsuitable for our purposes. These instruments were developed some years ago (4, 16, 17), and we assume that since then technological improvements have been made to NICUs, such as single rooms and greater possibilities for parental presence throughout the hospital stay. In the last decade, the NICUs have systematically developed models of nursing, such as NIDCAP and the kangaroo method. Also, the instruments we found studied both paediatric intensive care units (PICUs) and ordinary children units, not NICUs (4, 5, 17, 18, 20, 21), and we believe that the differences between an ordinary children's unit compared to a NICU could be of importance. There is a need for a slightly different survey with additional questions, because our population was ≥ 24 weeks (gestation age) to ≤ 3 months (after full-term birth), while the other surveys focused on a population of ≥ 3 months (after full-term birth) up to 18 years of age. A third difference is that in the ordinary children's unit, the parents are given time to attach to their child, while in our NICU, the parents are just starting the process of child attachment. McCormick et al. (19) reported important factors, which helped us develop the NSS. We recently learnt that Latour et al. (22) have simultaneously with us developed a survey for NICUs with items quite similar to ours. They report 5 categories: information, care and treatment, parental participation, organisation and professional attitude.

The purpose of studies on the quality of health care is to describe and improve practices in hospitals and communities. When children are patients, parents and other next of kin play a particular role in the treatment process. Due to all the aforementioned changes to NICUs, the increased focus on parents' experiences in this area and the age difference between PICUs and NICUs, we conclude that there is a need for a new or updated instrument for measuring parents' satisfaction with their child's health care.

Our purpose of this study was to develop and validate a survey to measure the level of satisfaction with the healthcare services on the part of parents/next of kin of sick newborns admitted to NICUs. We call the survey the Neonatal Satisfaction Survey (NSS). The recommendations of Polit & Beck and Haraldsen guided us in developing and testing self-report scales (23, 24).

The validation process was planned and contained literature review, views from parents to neonatal children, expert health personnel and a pilot study to validate content validity and statistical considerations.

Methods

Setting

The study took place in the NICU in a hospital located on the west coast of Norway. The emergency neonatal unit

holds 13 beds and treats patients with medical and minor surgical diseases. The unit treats patients between a gestation age of ≥ 24 weeks up to newborns aged 3 months, and on rare occasions, patients with a gestation age of < 24 weeks are treated.

The unit has one reception room for one patient at a time, four separate emergency rooms and four intermediate rooms each for two patients. The unit also has four kids/parents rooms for healthier children and one separate room for isolation purposes. Thus, parents can be situated with their child around the clock as long as the child is stable and does not have too many complicating issues, such as infection or the need for intensive care. The mean admission rate in the NICU is 20–25 patients each month.

The NICU admits newborns who are born with a disease or damage and who are at risk of developing diseases due to their premature status. Most of the newborns are in need of medical treatment and technical support, such as an incubator or respirator treatment due to breathing problems and immaturity. Most of the work entails monitoring and observing the newborns and responding properly in acute situations that often occur in premature babies.

Approximately 300 patients are admitted each year, of which $\approx 20\%$ are readmissions.

The inclusion and exclusion criteria

All family members ≥ 18 with a child admitted and who were staying in the NICU for more than 2 days were invited to join the pilot study, except for cases in which the child unfortunately passed away during their stay. The parents had to be able to speak and write fluent Norwegian.

Populations

Focus groups – Health personnel and parents. The expert group had nine professional health workers: three paediatricians, five nurses and one social worker. The parents' focus group contained ten parents who had a child admitted to a NICU. The National Parent Support Organization helped us to select the parents in the focus group. We developed an interview guide suitable for harvesting data. The focus groups were audio- and videotaped. All the content was transcribed and analysed based on the views of Giorgio and Rabiee (25, 26). We conducted a systematic text condensation that ended in thematic categories with items as the final outcome (27–30).

Parent sampling in the quantitative validation approach. Our population was parents of children that fulfilled the inclusion and exclusion criteria. During the sampling

period, 161 patients were admitted. Seventeen were readmitted, and 41 did not meet the eligibility criteria of admission ≥ 2 days. One child was excluded due to a gestation age of < 24 weeks. Parents of 14 patients were ineligible because they did not speak Norwegian and 29 for administrative reasons. This left 59 patients for the study. Due to single mothers, twins or triplets, the total sample thus consisted of 105 parents. All the respondents gave oral and written consent to participate after having read an information letter concerning the study.

Statistical considerations

Continuous measures were analysed by *t*-tests. Categorical variables were examined with chi-square tests. Internal analyses of each category were performed to see whether the items appeared to measure the same phenomenon. Cronbach's alpha is reported (23). A factor analysis was used to establish the number of subgroups and examine explained variance. A common factor analysis of the NSS helped to further validate our patterns in the survey. Due to the low number of respondents ($N = 105$), we decided to use the results as direction for the validation process. These data are reported in text rather than tables (23).

Ethical considerations

The respondents were parents of children with a gestation age as low as 24 weeks, and asking them to answer a large survey could perhaps be regarded as a burden. Participating in the survey might in itself increase parents' worries. At the same time, it is also likely that the parents felt empowered by answering questions and having the chance to state their opinions.

Due to the ethical considerations, we emphasised the voluntariness of participating in the study and of parents' right to withdraw from the study. We also emphasised that their participation or nonparticipation would not influence the treatment in the NICU. Due to the assumed vulnerability of the parents, we decided to carry out the interviews a few days prior to discharge and not during the initial crisis period. As the parents were admitted to the hospital together with their child, health personnel were close by in case any questions on the NSS triggered difficult emotions. In addition, parents were given the researchers' contact information. The project recruited five experienced nurses in the NICU to handle the consent forms and administer the survey.

The study was presented to the Regional Ethics Committee in Norway. The committee responded that as long as we interviewed the parents, the study was outside of their mandate. Nevertheless, we treated the parents as the vulnerable group, and we considered them to have been during this difficult time. All the respondents gave

oral and written consent to participate after having read an information letter concerning the study.

Results

Methodical stages of the study

Step 1. Literature review. The first research question entailed a review of the literature in all relevant search engines and websites along with educational texts on the topic of neonatal medicine and nursing. We found relevant literature to help develop the NSS (28–33). These studies focused on how to develop a survey and supported the validity of the questions in NSS. We also had methodological knowledge in forming categories based on studies focusing on special issues relevant for developing a survey for intensive care units (4, 16–18, 32).

As already mentioned in the introduction section, a Norwegian survey to measure parents' satisfaction was developed a few years ago (21). However, that survey covered experiences of parents of children with an age range from ≥ 3 months (after full-term birth) up to 18 years. Our child population had a gestation age of 24 weeks before birth to ≤ 3 months after full-term birth. Although the populations have some differences, we decided that 35 of the survey items were relevant as they corresponded with our literature review. Groven et al. (21) delineated six subcategories in their parents' satisfaction survey: 'nurses' care', 'doctors' care', 'organization', 'physical environment', 'information on medical tests' and 'information after discharge'. Groven's survey was also validated by Garrat et al. (5). In addition, we gathered demographic information on gender, age, whether the respondent is the mother or the father, travel time from the hospital, first language, level of education and occupational status of the respondent. We also gathered demographic information on the child: gestation age when born, multiparous birth, diagnosis and duration of stay. First step was completed in spring 2009, and 42 items were established.

Step 2. Focus group interviews with health personnel. We followed the advice of Latour et al. (32), to gather the health personnel's views of the NSS. We established an expert group in the NICU to ensure content validity and to discuss clinical, medical and methodological questions with personnel from the clinical field. We recruited nine persons to evaluate the preliminary NSS – two doctors and five nurses with at least 5 years of experience in an NICU, the social worker of the unit and the unit leader who is also a nurse. Based on a systematic analysis of the expert group's comments, we decided on only minor changes to the text of the chosen questions from the Groven's (21) survey. The NSS was then supplemented by the health personnel's point of views. Second step of

the NSS: focus group interview with health personnel (N = 9). Thirty items were added (total items for second step: 72). Step 2 was completed in autumn 2009.

Step 3. Focus group interviews with parents. Parents who experienced having their children admitted to an NICU then evaluated the third version of the NSS. Two national parent user organisations helped us recruit parents to evaluate their understanding of the NSS. Ten parents participated in focus group interviews. We searched for topics that parents found important, yet were missing in our NSS. We also investigated whether they found the questions relevant. Third step of the NSS: focus group interview with parents (N = 10). Fifteen items were added (total items for third step: 87). Step 3 was completed in spring 2010.

Step 4. Second focus group interview with health personnel. We also conducted a second expert focus group interview with nine health personnel to gather their opinions on the third step of the NSS, after harvesting the parents' data. We recorded and transcribed the interviews to make sure we did not omit important issues and that questions were based on the expert views. Only small changes were conducted, and six items were added (total items for fourth step: 93). Step 4 was completed in autumn 2010.

Step 5. The pilot study and content validity and statistical considerations. To assure that our population would be as representative as possible for validation purposes, we decided to include 100 parents or continue for 6 months, whichever occurred first. Admitted patients to the NICU from 01.10.11 to 31.03.12 were consecutively invited to the study if they were eligible. Nurses in the unit were also available for questions related to the pilot study. The objective of the pilot study was to test the NSS on a population of parents with a child in an NICU and to statistically validate the NSS.

Fifth and final step of the NSS: statistical item reduction with the support of factor analysis (N = 105, data not shown). We omitted 24 items (total items for fifth step: 69). The final step of the NSS was translated from Norwegian to English by a professional translator and back translated by our research team. Only small adjustments were made after the back translation. The NSS has not been tested in an English-speaking population. Step 5 was completed in spring 2012 (Fig. 1).

Content validity of the survey, extracted from literature and research

The literature review supplied important information on relevant topics to be included in our survey. Similar topics were described in different studies. These topics were nurses' and doctors' ability to show empathy, respect and

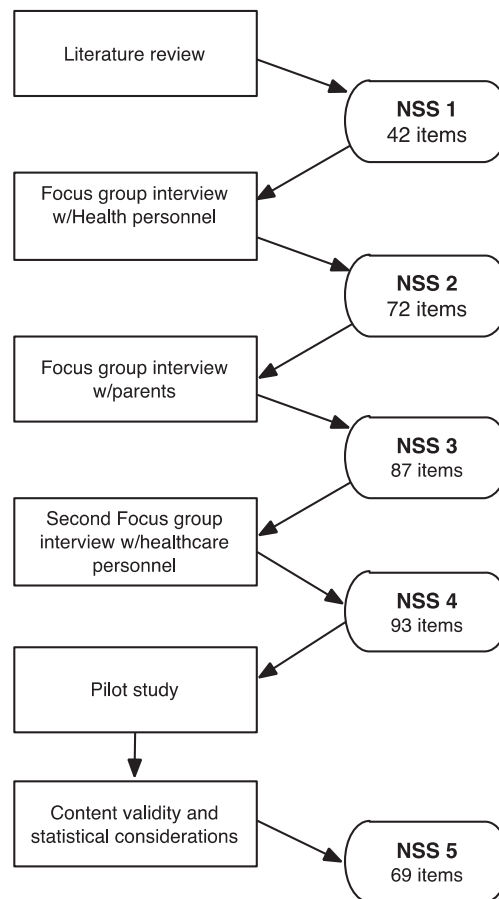


Figure 1 Steps in the validation process of NSS-13.

caring for the child; the availability of health personnel when parents needed to talk; health personnel's clinical competence to provide parents with information and to listen to them in decision-making; and physical environment (4, 18, 31, 32). In addition, Latour (32) points to the importance of having health personnel's views when developing a survey. The first step consisted of 25 items from Groven (21) and 17 items from the literature review, a total of 42 items.

The first expert validation of the survey. The expert focus group supported the first step but added views and new items in the areas of the child's nutrition, available information and visitors' utilities. The social worker who was present wanted questions on her role in the NICU, and we added some items, which were later omitted after a factor analysis. In addition, the experts' views resulted in an increase to 72 items.

The parents' validation of the survey – major issues. The parents had opinions on the importance of feeling safe in the demanding situation of having a child admitted to an NICU. They also suggested questions on how health personnel could help parents to cope. They recommended 15 new items, and thus, the third step of the survey yielded 87 items.

The second expert validation of the survey – major issues. The experts wanted to have questions rephrased and also suggested adding topics such as caring for the child and the anxiety of parents. The experts recommended 6 more items, and the fourth step of the survey contained 93 items. The main comment from the second expert group was that the survey seemed to cover all relevant topics (Table 1).

Quality validation of questions in the survey from a pilot study – major issues. Our validation of the survey took place in a population of parents, both mothers and fathers. We found significant differences between mothers and fathers on some variables. The mothers were more often alone with the child in the hospital and not in paid work compared to the fathers. For all other variables – age, education, relationship status, help from family, travel time to the hospital and language – no significant differences were found.

The parents (N = 105) seemed to understand the questions of the survey. We found very few blanks, but some of the questions were rephrased to fit better with the statistical analyses.

However, a few of the questions had a missing response rate exceeding 10%. We investigated these questions closely to see whether any should be omitted. The questions covered the following topics: nutrition, information on breastfeeding/breast milk, why the child was admitted, the social worker's role and information on available help after discharge. Our qualitative research showed small differences in categories compared to the

earlier described study (21), which was expected due to the differences in population.

Statistical validation of the Neonatal Survey – 13 categories (NSS-13). We analysed the internal consistency of each category, and Cronbach's alpha varied from 0.60 to 0.89. The highest internal consistency was found in the categories 'staff', 'doctors', 'nursing personnel', 'information' and 'visitors' (alpha values >0.80 but <0.90). The categories 'admission', 'anxiety', 'siblings', 'facilities' and 'discharge' held alpha values >0.70 but <0.80. The category 'nutrition' had an alpha value of 0.69. The lowest alpha value was found in the category 'trust' ($\alpha = 0.60$) (Table 2).

Common factor analyses suggested 21 categories, but reliability analyses suggested a better model when moving items to already existing categories. We therefore concluded with 13 categories as the best solution and also in quite good concordance with our qualitative research. Total variance explained by the 69 items was 84%. The validation process revealed overlapping items and items too detailed for our purposes, along with low factor loading values when examined with exploratory factor analysis, and a total of 24 items were omitted from the final version of the NSS-13. Demographics of the parents participating in the survey are presented in Table 3, and demographics of the parents' infants are presented in Table 4.

Discussion

Review of literature

The review of literature supplied us with information to validate the NSS. In the process of reviewing, we found studies where methods were described so poorly that we chose to exclude them. We decided to use papers that seemed to be of decent quality, in our opinion. During the review, we focused on topics related to our age group

Table 1 Important items (#) from literature and different focus groups^a

Literature review	Expert focus groups of health personnel (N = 9) 1st focus group	Expert focus groups of parents to neonatal children (N = 10)	Expert focus groups of health personnel (N = 9) 2nd focus group
Staff: ##1.1, 1.2	Admission: # 2.9	Admission: ## 2.7, 2.8, 2.10	Anxiety: # 4.2
Admission: ## 2.1, 2.2, 2.3, 2.4, 2.5, 2.6, 2.11	Nursing: ## 3.8, 3.9	Siblings: ## 5.1, 5.2, 5.3	Time off: # 7.2 8.8
Nursing: ## 3.1, 3.2, 3.3, 3.4, 3.5, 3.6, 3.7, 3.10	Anxiety: ## 4.1, 4.3, 4.4	Information: # 6.5	Discharge: # 11.2
Information: ## 6.1, 6.2, 6.3, 6.4	Doctors: ## 8.5, 8.7	Time off: # 7.1	
Doctors: ## 8.1, 8.2, 8.3, 8.4, 8.6	Nutrition: ## 10.1, 10.2, 10.3, 10.4, 10.5, 10.6	Trust: ## 12.5, 12.6	
Facilities: ## 9.1, 9.2, 9.3, 9.4	Trust: ## 12.4, 12.7		
Discharge: ## 11.1, 11.3	Visitors: ## 13.1, 13.2, 13.3, 13.4		
Trust: ## 12.1, 12.2, 12.3			

^aTwenty four items were omitted in the analysing process of the 1st and 2nd author.

Table 2 The Neonatal Satisfaction Survey – 13 categories

1) Staff (0.89) 2 items	2) Admission (0.78) 11 items	3) Nursing personnel (0.88) 10 items	4) Anxiety (0.78) 4 items	5) Siblings and other next of kin (0.79) 3 items
6) Information (0.85) 5 items	7) Timeout (0.75) 2 items	8) Doctors (0.89) 8 items	9) Facilities (0.71) 4 items	10) Nutrition (0.69) 6 items
11) Preparation for discharge (0.77) 3 items	12) Trust (0.60) 7 items	13) Visitors (0.85) 4 items		Total: 69 items

Cronbach's alpha reported in brackets.

Table 3 Demographics of parents participating in survey validation – the pilot study

Variables	Mother (N = 59)	Father (N = 46) ^a	p-value	Total (N = 105)
Age at admission, mean (SD)	28.93(5.86)	30.93(5.17)	0.073	
	N (%)	N (%)	χ^2	N (%)
Single mother				
Yes	5 (8)	0 (0)	0.023	5 (5)
Partly	14 (24)	5 (11)		19 (18)
No	40 (68)	40 (89)		80 (77)
Relationship status, N (%)				
Married	21 (35)	14 (31)	0.88	35 (34)
In relationship	37 (63)	30 (67)		67 (64)
Single parent	1 (2)	1 (2)		2 (2)
Level of education, N (%)				
Higher education > 4 years	6 (10)	4 (9)	0.96	10 (10)
Higher education <4 years	23 (39)	16 (37)		39 (38)
College	27 (46)	22 (49)		49 (47)
Grammar school	3 (5)	3 (5)		5 (5)
Work status, N (%)				
In paid work	34 (58)	38 (86)	0.023	72 (70)
In education	5 (8)	2 (5)		7 (7)
Working at home – unpaid work	2 (3)	0 (0)		2 (2)
Social security of some kind	17 (29)	3 (7)		20 (19)
Other	1 (2)	1 (2)		2 (2)
Travel time to hospital N (%)				
0–0.5 hours	15 (26)	12 (27)	0.96	27 (26)
0.5–1 hours	12 (20)	8 (18)		29 (19)
1–2 hours	16 (27)	11 (24)		27 (26)
More than 2 hours	16 (27)	14 (31)		30 (29)

^aOne father omitted all the demographics but answered the rest of the survey.

of children: ≥ 24 weeks to ≤ 3 months (16, 33). The literature review revealed that Conner & Nelson (16) identified 11 dimensions of care as important to parents whose infants received neonatal intensive care: assurance, caring, communication, consistent information, education, environment, follow-up care, pain management, participation, proximity and support. Although our categories

have different headings, they seem to cover most of the aspects described by Conner & Nelson (16).

McCormick et al. (19) found that the major predictors of parental satisfaction with neonatal intensive care were child health at the time of the interview, followed by sociodemographic factors and previous infertility treatment. These are factors we will explore in our planned main study.

Latour et al. (22) have developed a survey to measure satisfaction in NICUs with five categories. Our NSS-13 revealed 13 categories, but the items of the survey are quite similar to ours which strengthens the validity of our survey. The main difference of the study of Latour et al. (22) and ours is that our validation mainly was performed with qualitative methods and Latour et al. was performed with quantitative method.

Development of preliminary survey

We decided to use the survey from Groven (21), because it seemed to include many of the topics we found in the literature review stage, and Cleveland (33) supported the fact that several of the items in Groven et al. (21) also were relevant in an NICU. Therefore, we included these items in our NSS: for example, parents' need for good information, to take part in the treatment of their child, to have individually adjusted care and to form a therapeutic alliance with the nurses. Nurses should support parents emotionally and empower the parents. However, the surveys we found studied somatic children's units, and we consider the differences between an ordinary children's unit and an NICU to be of importance. Thus, we needed a somewhat different survey with additional questions. As stated earlier, our population was ≥ 24 weeks (gestation age) to ≤ 3 months (after full-term birth), while the Groven's (21) survey was intended for a population of ≥ 3 months (after full-term birth) up to 18 years of age. A third difference is that in the ordinary children's unit, the parents have had time to attach to their child, while in our NICU, the parents are just starting the process of child attachment. Although some of the comments from the expert group suggested that questions should be changed or paraphrased, we decided on minor changes only. We found the suggestions

Table 4 demographics of the parents' infant participating in the survey design. Infants (N = 59)

Variables	Number
Gestational age (weeks)	
>42	0
38–42	29
34–37	12
29–33	14
24–28	4
Multiparous birth	4
Primary diagnosis	
Syndrome	2
Infection	7
Blood sugar problem	2
Breathing problem	9
Food/weight problem	5
Heart disease	1
Observation	7
Other	7
Missing	19
Length of stay	
1 week	15
1–2 week	20
2–4 week	9
>4 week	14
Missing	1
Health characteristic	
Excellent	14
Very good	27
Good	15
Somewhat good	2
Missing	1

to be marginal and that eventual comparison with Groven (21) and Garrat et al. (5) could be biased if we changed the questions.

The purpose of forming an expert group was to ensure content validity of the survey and to discuss relevant questions from different perspectives to avoid omitting significant issues. We also found it important to conduct two expert focus group interviews to secure the latest step of the survey.

Some of the other questions were rephrased due to useful comments from the expert group. Comments from the expert group were on topics such as visits to the emergency unit, caring for the child, the availability of health personnel to the parents, availability of information, the anxiety of parents, nutrition of the child and visitors' utilities. We rephrased some of the questions to make them easier to understand. The second step of the content validity of the NSS resulted in 72 items.

We followed the recommendation of Haraldsen (24), who emphasises the importance of using language that can be understood easily by the intended population, and we tried to specify the questions with Haraldsen's advice

in mind. The main challenge was to rephrase questions without changing their meaning.

As a basis for the third step of the content validity of the NSS, the next step was to interview parents who had children admitted to a neonatal emergency unit (24, 32). The parent group regarded questions on trust, honesty and information as satisfactory. But the group was less satisfied with the questions concerning topics such as the physical environment for the parents, and they mentioned the fact that no questions addressed the father's role in the unit. The fathers received little attention in the unit, and they felt that they were regarded as an appendix to the mother and the child. Questions of privacy were raised, in addition to the difficulty of dealing with health personnel's secrecy. Parents also wanted questions on the danger of contamination. Questions on noise and disturbance in the unit were pointed out as another area to explore in the NSS. The parents also requested questions measuring parents' experience of stress, insomnia and anxiety, along with siblings' reactions to having a sick baby in the family. The parents also emphasised that the questions should be easy to understand, and they suggested some good rephrasing in accordance with the advice of Haraldsen (24). The focus group interviews with the parents resulted in an increase from 72 to 87 questions. These questions added subtleties to the NSS, making it more nuanced than Groven (21).

The fourth step was based on focus group interviews with a new expert group of health personnel. They suggested including questions regarding the social worker's role, which resulted in adding a few questions on that topic, along with questions on the cooperation between the neonatal unit and the children's unit in the hospital. However, these questions were omitted due to low values in the factor analysis. The fourth step of the NSS resulted in 93 items.

Pilot study – Content validity of the NSS in a population of parents of neonatal children

We gathered 105 valid NSS surveys, and very few items were left blank. This indicates that the respondents easily understood the questions in the NSS.

As expected, the mothers were more often alone with the child in the hospital. The father also had to take care of older siblings at home as they periodically were not allowed to visit the unit due to the risk of contaminating the neonatal child. Another difference between the mothers and fathers was that the mothers were significantly more likely to be unemployed, which is surprising as both men and women usually are employed in Norway and both parents normally benefit from paid childcare leave. We do not know whether the mothers quit their jobs when pregnant or were unemployed before the pregnancy.

The question of nutrition seemed to be somewhat misleading. The parents chose several alternatives to this question, and it was not possible to differentiate between primary nutrition and supplementary nutrition. Due to the documentation of nutrition, it was sometimes difficult to determine what type of nutrition the child had at different times. This issue is associated with the questions on breastfeeding information and is probably one area that can be improved on in the NICU. We changed from separate nutrition answers to satisfaction with different aspects of information, autonomy and knowledge of the various feeding categories.

In addition, some of the questions had to be rephrased to fit statistical analyses. One topic was the age of the child – we chose the count start as the gestational age. Another question that was omitted by more than 10% of the respondents was ‘whether the parents had enough information on what kind of milk the child was given and why’. We assume that the nonresponders fed their child with their own breast milk and that is why so many chose not to answer that particular question. According to law in Norway, the parents must consent before their child is fed with donor milk. Due to the strong emotions that can be associated with giving donor milk to children, we rephrased the question and added one asking if their child was fully fed by breastfeeding.

We changed some of the questions on why the child was admitted to the NICU. Diagnosis was listed, and the parents marked the most relevant one. They marked several diagnoses, probably because our formulation of the question was unclear. This was corrected in the revised NSS.

From the expert focus group, we were asked to include a question in the survey concerning the social worker’s role in the process. We found that 42% of respondents did not answer this question, and we decided to remove it.

The question concerning information on the assistance available after discharge was also left blank by about 12% of the respondents. Our focus was on the inpatients, so we decided to omit the question.

A short statistical validation of the pilot study

The alpha values demonstrated that the items in each category are internally related but not to the extent that the items should be omitted, and we concluded that the items in each category measure the same phenomenon. One exception was the low alpha values found in the category ‘cooperation’. The low alpha value in ‘cooperation’ may be due to a rather large number missing because only a few patients had been admitted to more than one hospital. We decided to omit the cooperation category because the parents had limited or no ability to say much about this topic. Although two of the categories had a low alpha value ($\alpha < 0.70$ but > 0.60), we decided to keep the questions/items. The explanation of

the low alpha value could be the low number of respondents, and we will replicate the analysis in our main study. The factor analyses recommended 21 categories. When analysing the focus group interviews, the expert group interviews and the survey test with 105 respondents with alpha values, we decided that 13 categories seemed to be the right choice. When conducting our future NSS-13 studies with more respondents in the future, we will replicate the statistics to explore the reliability of the NSS-13. The items of the NSS-13 explained 84% of the variance in the material.

Strengths and limitations

The focus group interviews may have favoured those who have the ability to engage in abstract thinking and to formulate themselves both orally and in writing, due to the open-ended questions that were asked (24). This could have excluded an important part of our population, and we consider it strength that we used method triangulation (both qualitative and quantitative methods). The quantitative methods employed instruments where respondents can indicate their points of view, and they do not have to formulate sentences themselves. Although the NSS has self-report answers, we also included a space for comments to highlight topics that were not identified in the earlier part of the study.

During the sampling period, 161 patients were admitted, and 41 did not meet the eligibility criteria of being admitted > 2 days.

Most surveys are validated in student populations. It is a strength that our population in the validation of the NSS was done with the same population we intend to investigate in future studies.

The lack of power calculation before the pilot study is a limitation. We could not conduct a proper factor analysis due to the low number of respondents ($N = 105$). Some statisticians recommend twenty observations for each variable, but Hair et al. (27) recommend a desired ratio of five observations per variable. In our sample of 69 items, the proper number of respondents/observations should be ≈ 350 . However, we used factor analysis as a supplement to our qualitative research and had statistical support for our category suggestions. The mentioned factor analyses will be conducted when we have harvested data in our main study, with the number of respondents appropriate for a valid statistical analysis.

The respondents in the health personnel group knew the interviewers, and this was considered both strength and a limitation. It was strength because all members of the focus groups could communicate easily and within safe environments and a limitation because some information might have been withheld due to colleague encouragement. The latter is not probable, although, due to the intention of all involved to contribute to the

development of the survey. The literature review was repeated right before the last submission, and we found that Latour et al. (22) have developed a survey with enough respondents to do a proper factor analysis. Our study contributes to a content validity from focus groups. Due to many similarities in the survey items of Latour (22) and ours, the two studies seem to support the main items. This strengthens the validation process. We consider it strength that both researchers, almost simultaneously, have identified the need for such a survey, and we will compare the statistical values in our next study to find the best statistical fit.

Summary

Based on the input of parents, doctors, nurses, patients' organisations and a thorough evaluation of each step in the validation process, we introduce the NSS-13 to measure parents' experiences/degree of satisfaction in the NICU. In this paper, we present the items and the categories in the NSS-13. For research purposes, we also present the survey in full text.

Conclusion

The NSS-13 was developed by literature reviews and focus group interviews to establish content validity. To improve the care in the various units employing the NSS-13, the design of NSS-13 focused on exploring areas in which the parents were dissatisfied with the care of their neonatal

children. The NSS-13 is suitable for measuring parents' satisfaction (or that of next of kin) of the NICU while their child is admitted. The survey can be used in full but is also suitable for investigating subcategories in the NICU. The results can be used for further research to increase parents' satisfaction in the future and also for further validation of the survey as we consider our work as the first of a series in validating the NSS-13.

Author contributions

All authors have contributed to the paper. The first and second author contributed to gathering of data and drafting the manuscript. The third author helped in drafting the manuscript. The first and last authors contributed in drafting, analysing and interpreting data.

Ethical approval

The ethical committee informed us that approval was not necessary for this kind of study, but we have followed ethical guidelines in the research process.

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APPENDIX

Categories	Items	The Neonatal Satisfaction Survey (NSS-13) developed by Hagen et al. 2013 Items
1 Staff	1-1	All in all, how satisfied/dissatisfied are you with the treatment your child received at the hospital?
	1-2	All in all, how satisfied/dissatisfied are you with the treatment you received as a parent at the hospital?
2 Admission	2-1	To what extent, did you perceive that one doctor had the main responsibility for treating your child?
	2-2	To what extent did you perceive that a set group of caregivers handled the treatment of you as parent?
	2-3	To what extent did you perceive that the caregivers cooperated on the treatment of your child?
	2-4	Did you perceive that the treatment of your child followed a set plan?
	2-5	To what extent did you perceive you were looked after during the admission process to the unit?
	2-6	To what extent did you perceive that your child was cared for during the admission process to the unit?
	2-7	To what extent did you perceive to be taken care of during the hospital stay?
	2-8	To what extent did you perceive the care of your child during the hospital stay?
	2-9	To what extent did you perceive having guidance and tutoring to enable you to take care of your child?
	2-10	I felt that both mother and father were treated in an equal manner at the unit
	2-11	While the child was admitted, did you experience any unforeseen delays?
3 Nurses	3-1	To what extent did you feel that nurses respected your total family situation?
	3-2	To what extent did you feel that nurses offered help with the child during the stay at the hospital?
	3-3	To what extent did you perceive that nurses informed you on their expectations of how you, as a parent, should handle your child?
	3-4	To what extent did you perceive that nurses showed compassion and cared for your child?
	3-5	To what extent did you perceive that nurses showed compassion and cared for you as a parent?
	3-6	To what extent did you perceive that nurses were interested in listening to your views as a parent?
	3-7	To what extent did you perceive that nurses gave relevant information in an understandable manner?
	3-8	To what extent did you perceive that nurses were close by the child during the stay in the hospital?
	3-9	To what extent did you experience that nurses were available for you as a parent?
	3-10	To what extent did you perceive that nurses were professionally competent?
4 Anxiety	4-1	While the child was admitted, did you perceive that personnel were optimistic and hopeful around your child?
	4-2	To what extent did you feel stress, anxiety or insomnia during the hospital stay?
	4-3	During admission of your child, were you ever afraid that your child would not survive?
	4-4	During admission of your child, were you ever afraid that your child would suffer from any future complications?
5 Siblings	5-1	I need guidance in order to understand the reactions of the siblings
	5-2	To what extent did the health personnel consider the reactions of the siblings?
	5-3	To what extent are you satisfied with the recreation areas for siblings?
6 Information	6-1	Were you properly informed of planned tests of your child during the stay in the hospital?
	6-2	Were you properly informed of why tests on your child were performed during the stay in the hospital?
	6-3	Were you properly informed of test results during the stay in the hospital?
	6-4	Were you properly informed of effects and side effects of medication administered to your child during the stay in the hospital?
	6-5	Did you perceive information from the personnel as adequate and adjusted to the situation during the stay in the hospital?
7 Timeout	7-1	Were you offered time off, like spending one night at home, while your child was at the hospital?
	7-2	Did you need to spend time at home during the hospital stay?
8 Doctors	8-1	To what extent did you perceive that doctors showed compassion and care for the child?
	8-2	To what extent did you perceive that doctors showed compassion and care for you as a parent?
	8-3	To what extent did you perceive that the doctors listened to you as a parent?
	8-4	To what extent did you perceive that the doctors explained in an understandable way?
	8-5	To what extent did you perceive that the doctors offered adequate information regarding the prognosis of your child?
	8-6	To what extent did you perceive that doctors seemed professionally competent?
	8-7	To what extent did you perceive that the doctors respected your family situation
	8-8	To what extent did you perceive that the doctors showed that they were available for you as a parent?
9 Facilities	9-1	What is your opinion of the showers/baths/toilets in the unit
	9-2	What is your opinion of the calm atmosphere in the unit
	9-3	What is your opinion of the facilities in the unit (food, relaxing room, sleeping room, breastfeeding room)?
	9-4	What is your opinion on the facilities concerning privacy, dressing rooms, confidentiality?

Appendix. (Continued)

10 Nutrition	10-1	If your child was fed with milk substitutes, were you given enough information of the substitute?
	10-2	Were you given the opportunity to take part in the decision-making of choosing nutrition?
	10-3	Were you informed on the milk substitute?
	10-4	To what extent were you satisfied of the information of how your child was fed?
	10-5	To what extent were you satisfied with the information of the nutrition your child was given?
	10-6	To what extent were you satisfied with the information of what kind of food your child received?
11 Discharge	11-1	In your opinion, did you receive the necessary information of the time after discharge?
	11-2	To what extent did you feel confident to care for the child after discharge from the hospital (breast feeding, medication etc.)?
12 Trust	11-3	Did you get enough information of how to act if your child relapses and is in need of medical care?
	12-1	Do you consider that your child has been the victim of malpractice in anyway?
	12-2	Were you ever angry, upset or disappointed during admission?
	12-3	In your opinion, did the personnel provide your child with adequate pain relief?
	12-4	Did you experience that health personnel did everything in their power to relieve stress for your child?
	12-5	I was in need of a follow-up or guidance to sort my reactions due to the child's illness and admission
	12-6	I perceived that the health personnel was respectful and empathic in our situation
12-7	During the stay in the hospital, would the health personnel call you upon any changes in your child (when you were not present)?	
13 Visitors	13-1	To what extent were you satisfied with the visiting areas in the unit?
	13-2	To what extent were you satisfied with the units' routines for the visitors
	13-3	To what extent were you satisfied with the facilities for relatives?
	13-4	To what extent were you satisfied with the facilities when other patients had visitors?

Paper II

RESEARCH ARTICLE

Open Access



Validation of the Neonatal Satisfaction Survey (NSS-8) in six Norwegian neonatal intensive care units: a quantitative cross-sectional study

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Abstract

Background: The experience of having their new-borns admitted to an intensive care unit (NICU) can be extremely distressing. Subsequent risk of post-incident-adjustment difficulties are increased for parents, siblings, and affected families. Patient and next of kin satisfaction surveys provide key indicators of quality in health care. Methodically constructed and validated survey tools are in short supply and parents' experiences of care in Neonatal Intensive Care Units is under-researched. This paper reports a validation of the Neonatal Satisfaction Survey (NSS-8) in six Norwegian NICUs.

Methods: Parents' survey returns were collected using the Neonatal Satisfaction Survey (NSS-13). Data quality and psychometric properties were systematically assessed using exploratory factor analysis, tests of internal consistency, reliability, construct, convergent and discriminant validity. Each set of hospital returns were subjected to an apostasy analysis before an overall satisfaction rate was calculated.

Results: The survey sample of 568 parents represents 45% of total eligible population for the period of the study. Missing data accounted for 1,1% of all returns. Attrition analysis shows congruence between sample and total population. Exploratory factor analysis identified eight factors of concern to parents, "Care and Treatment", "Doctors", "Visits", "Information", "Facilities", "Parents' Anxiety", "Discharge" and "Sibling Visits". All factors showed satisfactory internal consistency, good reliability (Cronbach's alpha ranged from 0.70–0.94). For the whole scale of 51 items a 0.95. Convergent validity using Spearman's rank between the eight factors and question measuring overall satisfaction was significant on all factors. Discriminant validity was established for all factors. Overall satisfaction rates ranged from 86 to 90% while for each of the eight factors measures of satisfaction varied between 64 and 86%.

Conclusion: The NSS-8 questionnaire is a valid and reliable scale for measuring parents' assessment of quality of care in NICU. Statistical analysis confirms the instrument's capacity to gauge parents' experiences of NICU. Further research is indicated to validate the survey questionnaire in other Nordic countries and beyond.

Keywords: Parents' satisfaction, NICU, Health care, Neonatal, Survey, Validity, Reliability

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Background

Approximately 10% of all new-borns in Norway require advanced health care soon after birth [1]. For parents, the experience of having their new-born infant admitted to an intensive care unit (NICU) can be extremely distressing. Subsequent risk of post-incident-adjustment difficulties are increased for parents, siblings, and affected families. A protective factor is a positive association between parent satisfaction with neonatal health care and parents ability to provide need-based care for their child(ren) [2–4]. When this includes delivering treatment to infants, better compliance is achieved and sustained by parents who report a higher level of satisfaction with neonatal health care [5–7].

Systematic screening of patient satisfaction should therefore be an essential part of quality-monitoring and quality improvement initiatives [8, 9]. By monitoring the patients' experiences, hospital units gather data which can be used to guide changes towards improved service provision, not only during the inpatient phase but also, by implication, after discharge [8].

Several instruments have been developed to gauge parent satisfaction with care in ICUs [5, 10–12], including assessment of mothers satisfaction with intrapartum care and childbirth [6]. Instruments developed to measure parent satisfaction with care in neonatal ICU (NICU) are few in number [13, 14], and none are developed for use in Scandinavia. Latour (2012) recently developed such a questionnaire in the Netherlands, and Sawyer (2014) has done the same with a focus on care provided for very pre-term infants in the U.K. With these considerations in mind, there is a pressing need to develop an instrument which measures parent satisfaction with care in NICU. Our first endeavour is to validate such an instrument for use in Scandinavia.

NICUs in Norway treat approximately 6000 children each year. Of these, about 60% are born at gestation (age \geq 37 weeks), 22% are born between 34 and 37 weeks, and about 18% are born at 34 weeks or less [15].

Norwegian national guidelines for health personnel aim to help parents give optimal care for their children, especially under circumstances considered to be personally challenging or difficult for families. Parents have established legal rights to be with their children when they so wish, and to this end, they receive mandatory information pertinent to their child's health status. There is also explicit recognition that parents have a right to participate actively in decision-making processes about their child's health care [16, 17].

The aim of this study is to validate the Neonatal Satisfaction Survey (NSS-13) [18] in six Norwegian NICUs. The survey measures parents' level of satisfaction with the care provided for their premature or sick infant. The selected NICUs are in different regional hospitals spanning a wide

geographical area with a diversity of urban and rural catchment areas.

Methods

Questionnaire development

In a former study [18], the Neonatal Satisfaction Survey (NSS-13) questionnaire was developed by a phased structured process intended to deliver a valid and discriminating survey tool. To establish convergent/concurrent and discriminant validity, the process started with a literature review which sought to extract "gold standard" for quality of care in NICUs.

In preparation for the pilot study [18], we included questions from Garrat et al.'s earlier informal survey [5] which included criteria for quality of hospital health care established by government decree in Norway [19].

Content validity (or face validity) refers to expert opinions on whether the scale items represent the proposed domains of concepts that the questionnaire is intended to measure. In order to establish what these may be, we convened a focus-group with participants selected from health personnel with relevant experience and expertise ($n = 18$). Also included were parents who had experiences from NICU ($n = 10$). They were asked to review a list of questions for relevance, clarity, and readability as well as to propose additional questions.

Two control questions, with an identical rating scale, measuring overall satisfaction were added to advance the process of developing the NSS-13 [20–22]. Content validity was tested on a small sample of 105 respondents by using the NSS-13 (pilot study) [18].

Having collated this baseline information, the next step in this project was to collect data required for a formal evaluation of the NSS-13 using factor analytic techniques. The power calculation was based on the previous studies. Hair et al.'s. [23] recommend a ratio of five observations per variable.

Measurement

The NSS-13 questionnaire contains 69 items derived from 13 categories or themes relevant to parents' satisfaction with care provided in NICUs. Themes are Staff, Admission, Nursing Personnel, Anxiety, Siblings and Other Next of Kin, Information, Time Out, Doctors, Facilities, Nutrition, Preparation for Discharge, Trust, and Visitors. An English language version of the NSS-13 was developed by translating to English and then back to Norwegian by professional translators.

Participant procedure

Participants of this study were Norwegian or English-speaking parents admitted to one of the six NICUs whose stays had lasted for more than two days. The infants' gestation age ranged from 24 to 42 weeks. The NICUs

admitted also infants up to 3-months after birth. The self-administrated questionnaire was given to the parents a few days before they were due to leave hospital, in order to facilitate a calm atmosphere. Parents with multiple births received only one questionnaire and those whose children passed away while in the unit were excluded from this study.

Data collection

The first author contacted the heads of 12 NICUs in Norway to invite their participation in the study. Six of the units could not participate because of an overload of studies at the time. Agreement was obtained from six units, each of which would collect at least 100 completed questionnaires. These six units are in a geographical spread area, with a variety of universities and local hospitals (level 2–3), and can therefore represent a valid selection of the NICU's in Norway. Once this had been agreed, the multi-centre prospective cohort study could proceed and was conducted between September 2015 and October 2016.

Participating NICUs varied in size from 6 to 21 beds (mean 12.5) and treated from 253 to 500 patients each year. Two NICUs are university hospitals, and the rest have regional or local catchment areas. Three units treated infants with \geq GA 23, and the rest cared for newborn infant with GA 26–30.

The first author introduced the study for the nurses in the units, and three research assistants were responsible for questionnaire distribution and collection. The research protocol to be followed was distributed to all unit nurses and were placed in a prominent position within each unit's nurses' station. During the collection of data period, the first author had regular contact with research assistants by telephone and email. Some units were also visited during the data collection phase.

As discharge approached, the research assistant contacted the infant's next of kin to secure their informed consent to take part in this study. The research assistant left a copy of the self-report questionnaire with parents who had agreed to take part. Confidentiality arrangements were explained, as was the protocol, that no completed questionnaires would be read by anyone working at the unit. The participants used about 30 min to complete the answering of the survey.

Respondents provided demographic information about themselves and their infant (Tables 1 and 2). To avoid sampling errors, we carried out an attrition analysis for each hospital because of the inclusion criteria (Table 3).

Data analysis

Descriptive statistics were first conducted. All items used in the survey were first analysed by the descriptive information given. Mother and father demographic differences were analysed with the Pearson chi-square test, (p value

set to ≤ 0.05). Correlations were tested by using Spearman rho. All significant tests are two-tailed.

Factor analysis was then used for data reduction in order to assess the underlying dimensions - or factors - of the questionnaire. The factor extraction was based on the principal component method, using the total variance of all variables (23). To assess the appropriateness of the factor analysis regarding sampling adequacy (high level of multicollinearity), the Kaiser-Meyer-Olkin (KMO) statistic and the Bartlett's test of Sphericity were used. The KMO varies from 0 to 1, and predicts the likelihood of the data to factor well based on correlations and partial correlations. KMO should be larger than 0.5 (23). The Bartlett's test of Sphericity tests the null hypothesis that the inter-correlations matrix stems from a population in which the variables have no correlations (23).

The factor loading of variables on a particular factor indicates the correlation between the variable and the factor, and should be higher than 0.3 in order to contribute to the overall KMO. Variables with factor loadings below 0.30 were eliminated.

Initially, we decided to remove 12 of the 15 items that did not significantly correlate with other questions. All six questions about nutrition were omitted from the factor analysis along with two questions containing staff caring about the infants' stress and pain, unexpected waits (latency) in the unit, personnel communicating hope, children given the wrong treatment, and the parents' need for follow-up regarding their own reactions. The three other questions regarding two items related to whether the parents were offered or needed a break from the NICU and information about the result of tests seem to be too clinically important to be removed at this stage.

Through a process of different exploratory factor analyses, we ended up with a final solution with eight factors. The basis for finding this number of factors was the Latent Root Criterion (eigenvalues larger than 1), which is a measure of the variance explained of each factor compared to the total variance. The factor solution used the orthogonal rotation method Varimax (23).

To establish questionnaire reliability (repeatability, stability and internal consistency), Cronbach's alpha, average variance extracted, and inter-subscale correlations were calculated. The total score might be biased, especially for small sample sizes, because the item itself is included in the total score [24]. To reduce bias, a corrected item-total correlation was also calculated. This is a correlation of individual questions with the scale total omitted; a coefficient of around 0.3 is considered acceptable [14]. To assess discriminant validity we applied the Fornell-Larcker criterion [25], where the average variance-extracted values (AVE) for any two latent constructs are compared with the square of the correlation estimate between these two constructs. Discriminant validity is present when AVE is

Table 1 Demographics of parents participating in the Neonatal Satisfaction Study

Variables	Mother (N = 312)	Father (N = 256)	X ² -test p-value	Total (N = 568)
Age at admission, Mean (SD)	30.09 (5.50)	33.10 (6.94)		
	N(%)	N(%)		N
Marital status			0.599	
Married/In relationship	300 (96.5)	247 (97.2)		547
Divorced/Single parent	11 (3.5)	7 (2.8)		18
Total	311 (100)	254 (100)		654
Level of education			0.013	
Higher education > 4 years	76 (24.4)	50 (19.7)		126
Higher education < 4 years	108 (34.6)	66 (26.0)		174
College	113 (36.2)	126 (49.6)		239
Grammar school	15 (4.8)	12 (4.7)		27
Total	312 (100)	254 (100)		566
Work status			0.001	
In paid work	217 (69.6)	232 (90.6)		449
Not paid work/education	95 (30.4)	24 (9.4)		119
Total	312 (100)	256 (100)		568
Travel time to hospital			0.404	
Less than 1 h	156 (50.0)	137 (53.5)		294
More than 1 h	156 (50.0)	119 (46.5)		275
Total	312 (100)	256 (100)		

Cross-tabulation and Chi-square tests**Table 2** Demographics of the parents' infant (N = 352) participating in the Neonatal Satisfaction Study

Variables	Total (%)
Was your child premature or born at term?	
Premature (< 37 weeks)	245 (70)
Born at term (≥ 37)	107 (29)
Missing	2 (1)
Total	352
Multiple birth	29 (0.82)
Length of stay	
< 1 week	93 (29)
1–2 weeks	104 (32)
2–4 weeks	58 (18)
> 4 weeks	62 (19)
Missing	8 (2)
Total	325
Parents' evaluation of the child's health (N = 568)	
Good	532 (94)
Bad	22 (4)
Missing	9 (2)
Total	568

larger than the squared correlations [25]. The items used for the factor modelling are originally measured on a 1–5 scale. In order to present results of the different factors in percentage rates, they have been transformed to a 0–100 scale.

Ethics

The study is conducted according to the Helsinki declaration. This project was first presented to the Regional Committees for Medical and Health Research Ethics which reported that the project was outside its mandate (2015/386). The project is approved from the Norwegian Data Protection Officials. All the respondents were asked to give oral and written consent to participate after having read an information sheet about the study which emphasized that participation was voluntary and that parents could withdraw from the study at any time.

Results

The study included questionnaire returns from 568 parents of whom 312 (54%) were mothers and 256 (45%) fathers (Table 1). One father had to be excluded because he had more than 20% missing. The response rate for the six hospitals participating in the study varied from 33 to 66%, and the mean was 45% (Table 3). The level of missing data is low (mean 1.1%) for the final survey, which suggests that the questionnaire is acceptable to respondents.

Table 3 Dropout calculation and average of the selection and population from NICUs in 6 hospitals

Dropout calculation and average of the selection and population from 6 hospitals								
	Unit 1 (level 2) N(%)	Unit 2 (level 3) N(%)	Unit 3 (level 3) N(%)	Unit 4 (level 3) N(%)	Unit 5 (level 2) N(%)	Unit 6 (level 2) N(%)	Sum population N(%)	Sum selection ^a
Number of patients admitted per year (2015) Population	330	439	253	255	196	232	1705	
Number of infants admitted during the collection period Population	150	322	141	226	169	167	1175	
Quantity after inclusion criteria Population	95 infants thereof 5 TV = 89 families	203 infants thereof 11 TV = 192 families	85 infants thereof 6 TV = 79 families	139 infants thereof 11 TV = 128 families	132 infants thereof 4 TV = 128 families	109 infants thereof 4 TV = 105 families	763 infants thereof 41 TV = 722 families	
Number of families who have answered	59	64	40	53	56	53	325	
Answers %	66%	33%	51%	41%	44%	50%	45%	
Gestational age Population								
24–28 weeks(%)	5(5.2) (1TV-par)	15(7.3) (2TV)	6(7.0) (2TV)	9(6.4) (1TV)	6(4.5)	2(1.8)	43(5.6)	
29–33 weeks(%)	14(14.7) (2 TV)	66(32.5) (7TV)	18(21.1) (2TV)	30(21.5) (3TV)	19(14.3) (2TV)	20(18.3) (2TV)	167(21.8)	
34–37 weeks(%)	28(29.4) (2 TV)	60(29.5) (2TV)	33(38.8) (2TV)	44(31.6) (7TV)	33(25) (3TV)	35(32.1) (2TV)	233(30.5)	
38–42 weeks(%)	47(49.4)	62(30.5)	27(31.7)	56(40.2)	70(53)	50(45.8)	312(40.8)	
> 42 weeks(%)	1(1.0)	0	1(1.1)	0	4(3.0)	2(1.8)	8(1)	
Total number of infant Population	95(100)	203(100)	85(100)	139(100)	132(100)	109(100)	763(100)	
Total number of infant Selection	63(66%)	69(33%)	44(51%)	59(42%)	58(44%)	54(49%)	347(45%)	
Gestational age Selection								
24–28 weeks(%)	4 (6.8)	8(12.5)	1(2.5)	5(9.4)	5(8.9)	1(1.8)	24(7.4)	
29–33 weeks(%)	11(18.6)	19(29.6)	16(40)	11(20.7)	7(12.5)	19(35.8)	83(25.6)	
34–37 weeks(%)	19(32.2)	23(35.3)	12(30)	13(24.5)	12(21.4)	19(35.8)	98(30.3)	
38–42 weeks(%)	22(37.3)	12(18.7)	10(25)	20(37.7)	30(53.5)	11(20.7)	105(32.5)	
> 42 weeks(%)	3(5.1)	2(3.1)	1(2.5)	2(3.7)	2(3.5)	3(5.6)	13(4)	
Total families	59(100)	64(100)	40(100)	51 (96.2) 2 missing	56 (100)	53 (100)	323(99.3)	

Table 3 Dropout calculation and average of the selection and population from NICUs in 6 hospitals (Continued)

		Dropout calculation and average of the selection and population from 6 hospitals						Sum selection ^a
		Unit 1 (level 2)	Unit 2 (level 3)	Unit 3 (level 2)	Unit 4 (level 3)	Unit 5 (level 2)	Unit 6 (level 2)	Sum population
		N(%)	N(%)	N(%)	N(%)	N(%)	N(%)	N(%)
Length of stay								
Population								
< 1 week(%)		32(35.9)	59(30.7)	24(30.3)	53(41.4)	60(46.8)	62(59)	290(40.2)
1–2 weeks(%)		39(43.8)	72(37.5)	28(35.4)	29(22.6)	38(29.6)	22(20.9)	228(31.6)
2–4 weeks(%)		13(14.6)	36(18.7)	18(22.7)	25(19.5)	16(12.5)	18(17.1)	126(17.4)
> 4 weeks(%)		5(5.6)	25(13)	9(11.3)	21(16.4)	14(10.9)	3(2.8)	77(10.6)
Total families		89 (100)	192(100)	79(100)	128(100)	128(100)	105 (100)	721
Length of stay								
Selection								
< 1 week(%)		21(35.6)	19(29.6)	6(15)	20(37.7)	20(35.7)	10(18.8)	96(30.2)
1–2 weeks(%)		20(33.9)	17(26.5)	16(40)	12(22.6)	19(33.9)	18(33.9)	102(32.1)
2–4 weeks(%)		9(15.2)	14(21.8)	6(15)	10(18.8)	4(7.1)	15(28.3)	58(18.2)
> 4 weeks(%)		9(15.2)	11(17.1)	11(27.5)	9(16.9)	12(21.4)	9(16.9)	61(19.2)
Total		59(100)	61(95.3)	39(97.5)	51(96.2)	55(98.2)	52(98.1)	317(97.5)
			3 missing	1 missing	2 missing	1 missing	1 missing	

Dichotomization of the parents' perception of their child's health is set to good (excellent, very good, and good) and to bad (from fairly good to bad)

^aThe different total Ns are explained by different populations as shown in the first column in the table

The six hospitals registered the total number of children admitted to their respective care units during the study period, both in total and split according to the variables infant “gestation age” (*GA*) and “length of the stay” (*length-of-stay*). This makes it possible to do a simple comparison of the sample and the targeted population, but only on these two specific variables. The two variables are, however, measured by ordinal scales with very few categories (*GA* has four categories and *length-of-stay* has five categories). This makes it difficult to test the significance of the difference between the sample and the population on these two variables. We are therefore only able to give some rough indication of the representativeness of the sample. This is done by calculating the Spearman rank correlation between the sample and the population on the basis of the two variables. Both the age and the length-of-stay distributions seem to be reasonably represented in the sample. The strongest correlations are found in the three sub-samples unit 1, unit 4, and unit 5 (correlations between 0.9 and 1.00). When taking the above descriptive variables into consideration, the two populations do not appear to differ much from one another.

The mean age of the respondents in the sample is 30.09 years (SD 5.50) for the mothers and 33.10 years (SD 6.94) for the fathers. There was a significant difference of education level between mothers and fathers. More mothers (59%) had a higher education (≥ 4 years) compared to fathers (46%), and more mothers (30%) were in unpaid work/education compared to fathers (9.4%) (Table 1).

Most parents (94%) characterized their child’s health as good, and 4% characterized it as bad. Out of the 352 infants included in the study, 70% were born with $GA \leq 36.9$. The length of stay was from 2 days to about 4 weeks [median, 2 weeks (Table 2)].

Factor analysis

After running exploratory factor analyse several times, as explained in the method section, eight factors comprising 51 variables (questions) were finally extracted. This final questionnaire with 51 items in eight factors explained 53.27% of the scale’s variance, and the correlations between questions were acceptable ($KMO = 0.938$, and the Bartlett’s test of Sphericity gave $\chi^2 = 4813.142$. With $df = 1275$, the significant level of the null hypothesis was far below 0.05 ($P < 0.0001$)).

We further confirmed the reliability/convergent validity of the final version of the NSS (see Table 4). In each factor, the Cronbach’s alpha was above 0.7 for all the items, and the inter-subscale correlation was between 0.70 and 0.94. Average variance extracted (AVE) for the eight factors were mainly above the recommended level of 0.50. The only exception was the *Care and treatment* factor showing an AVE of 0.464. Discriminant validity as

present for all the eight factors, as the AVE’s are larger than any of the squared correlations between pair of factors (Tables 4 and 5).

The total alpha of all 51 questions was 0.949. In the corrected item total correlation, the items correlated between 0.362 and 0.718, except for three items concerning questions about the parents’ worries about their child not surviving and after-effects and one item regarding facilities (0.115, 0.136, 0.284). We did not omit these questions because we consider these items to be of clinical importance when measuring the quality of health in NICUs. Pallant (2010) recommends looking at alpha if an item is deleted, and if any of the values in this column are higher than the final alpha value, removing the item [26]. This was not necessary in our analysis. The structure of components, their loadings, the percentages of variance explained by each factor, and the number of items are described in Table 4.

The standardized factor loadings of the items within the factors, from the rotated factor matrix, were as follows: Care and Treatment, 0.709–0.325; Doctors, 0.800–0.325; Visit, 0.806–0.679; Information, 0.713–0.387; Facility, 0.646–0.470; Parent Anxiety, 0.849–0.510; Siblings, 0.818–0.588; and Discharge, 0.635–0.502.

Convergent validity was explored by examining the relationship between the NSS scale and the questions measuring overall satisfaction with care by using the Spearman’s rank correlations (Table 6). Total scores on the NSS were (1) “All in all, how satisfied or dissatisfied are you with the treatment the child/children received at the hospital?” and (2) “All in all, how satisfied or dissatisfied are you with how you as a next of kin were treated?” On overall question 1, 46 of 51 items correlated at the 0.01 significance level. Three items were correlated at the 0.05 significance level, and two questions did not correlate. On overall question 2, 47 items were correlated at the 0.01 significance level, two items were correlated at the 0.05 significance level, and one item did not correlate.

The strongest correlation between all-in-all question 1 (infant satisfaction) was found in the item “To what extent did you experience that the child/children were taken care of later in the process?” (0.353). The weakest correlation was between overall question 1 and the item “While the child/children were admitted, were you at any time afraid that the child/children would have delayed injury/after-effects?” (0.033).

The strongest correlation found between all-in-all question 2 (parents satisfaction) and the related items was “To what extent did you experience that you were taken care of later in the process?” (0.488). The weakest correlation was between question 2 and the item “During the period of the child’s/children’s admission, were you at any time afraid that the child/children would not survive?” (–0.028) (table not shown).

Table 4 Exploratory factor analysis and reliability testing results of the NSS-8^a

Factors	Name of each domain	Number of items	Eigenvalues			Internal reliability Cronbach's α	Average variance extracted (AVE)
			Total	% of variance	Cumulative %		
F 1	Care and Treatment	22	9.150	17.942	17.942	0.94	0.464
F 2	Doctors	9	5.898	11.565	29.507	0.91	0.697
F 3	Visit	4	3.118	6.113	35.621	0.91	0.796
F 4	Information	4	2.006	3.933	39.554	0.81	0.679
F 5	Facility	4	1.944	3.811	43.364	0.72	0.552
F 6	Parent anxiety	3	1.835	3.597	46.962	0.74	0.665
F 7	Discharge	3	1.816	3.560	50.522	0.70	0.639
F 8	Siblings	2	1.402	2.749	53.271	0.72	0.736

^aVarimax rotation

Correlations between the 8 factors in the questionnaire and the two global questions of satisfaction provided support for the convergent validity of the questionnaire (Table 6). Factor 1 “Care and Treatment” correlated most strongly with both overall questions (0.394 and 0.514), and factor 6 “Parent Anxiety” had the weakest correlation (0.135 and 0.155) at the 0.01 level. The correlation was significant at the 0.01 level for all components except from component “Siblings” who was significant at the $p < 0.05$ level.

Parents' satisfaction rates measured in percentage rates for all the eight factors and the two overall quality measures are shown in Table 7. We can see that overall the satisfaction rates are high and SDs are low, suggesting little disagreement in the evaluation of services. The highest satisfaction rate was on factor 1 “Care and Treatment” with a score of 86%, including 22 items. The question “To what extent did you experience that the child/children were taken care of upon arrival in the component at the unit?” scored 95%. Factor 3 “Visit” and factor 5 “Facility” have a shared 2nd place at 85%. The question on factor 5, offering of food/rest, loading, pump room, etc., was the highest item with a score of 89%. The lowest rate was on factor 8 “Siblings”, with a

score of 64%. Factor 2 “Doctors” was placed on 4th place, with a score of 81%. The lowest satisfaction rate of all 51 items was in factor 2 on the item “To what extent did you experience that one doctor had the principal responsibility for the child?” with a score of 52%.

Discussion

The aim of this study was to validate the NSS-13 and develop a questionnaire that can be used to assess parent satisfaction and experiences with care during the birth of a preterm baby or sick new born hospitalized in a NICU. For full details and comparison of NSS-13 and NSS-8 we refer to Hagen et al. (2015) [18].

After the validating process of NSS-13 the questionnaire was reduced to eight factors (NSS-8). The main findings were that NSS-8 is a suitable instrument to measure parents' satisfaction in NICUs. Statistical analysis showed that the NSS-8 is valid for its purpose, and the results indicate that the NSS-8 has optimal quality. To prevent from acquiescence bias, we have balanced the items in positively and negatively worded questions. However, early-assessed satisfaction may be influenced by expectations, many mothers gave birth unexpectedly to a premature infant, and this could have a negative

Table 5 Squared correlations between the constructs and average variance extracted (on the diagonal)

	F1	F2	F3	F4	F5	F6	F7	F8
F1 Care and treatment	.464							
F2 Doctors	.456**	.697						
F3 Visit	.286**	.194**	.796					
F4 Information	.438**	.370**	.178**	.679				
F5 Facility	.267**	.183**	.227**	.145**	.552			
F6 Parent anxiety	.040**	.020**	.025**	.027**	.044**	.665		
F7 Discharge	.219**	.158**	.085**	.176**	.051**	.012*	.639	
F8 Siblings	.254**	.124**	.070**	.115**	.085**	.077**	.083**	.736

**Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed)

In the table above, we see that all the average variance-extracted values (bold) are larger than any of the squared correlations between pairs of constructs, that is, discriminant validity is established for all constructs

Table 6 Convergent validity. Correlation between overall patient satisfaction and components

Factors	Overall item 1	Overall item 2
	Treatment of the infant	Treatment of parents
F1 Care and Treatment	.394**	.514**
F2 Doctors	.323**	.385**
F3 Visit	.229**	.286**
F4 Information	.352**	.393**
F5 Facility	.232**	.263**
F6 Parent anxiety	.135**	.155**
F7 Discharge	.232**	.249**
F8 Siblings	.179*	.162*

Spearman's rank correlation

** = correlation is significant at the 0.01 level (2-tailed)

* = correlation is significant at the 0.05 level (2-tailed)

impact on satisfaction ratings. It may also be difficult to distinguish between satisfaction with the childbirth experience and satisfaction with the care received. It is therefore suggested to define dimensions of perinatal care, such as staff attitudes and behaviour, information, and environment and make sure that satisfaction can be measured for each individual dimension. This may help refine satisfaction assessment and more accurately delineate aspects of care [27].

The items in the NSS-13 were developed from a comprehensive review of literature, along with existing tools, and based on expert ratings; the content validity of the questionnaire was acceptable. High Cronbach's alpha and Spearman rank correlation also confirmed the reliability of the questionnaire. There are many different methods to assess construct validity. In this study, we have measured the construct validity of NSS-13 by using exploratory factor analyses and decided on 8 dimensions (NSS-8). The survey was subject to a series of testing

Table 7 Satisfaction rate with the different areas in NSS-8 (percentage rate)

Factors and global items	Satisfaction rate (%)	St.dev.
F1 Care and treatment	86.16	12.21
F2 Doctors	80.66	16.83
F3 Visit	84.76	16.62
F4 Information	79.92	16.83
F5 Facility	84.89	16.53
F6 Parent anxiety	70.20	22.82
F7 Discharge	75.29	18.67
F8 Siblings	64.43	18.89
Overall quality 1	90.51	23.77
Overall quality 2	86.57	22.94

Satisfaction scores and satisfaction rates for individual items and eight factors were reported. The satisfaction rate was calculated in accordance with the following formula: $Px = \frac{(x - 1) \times 100}{s - 1} = \% \text{satisfaction rate/item}$

processes to assess its reliability and validity. All eight dimensions were similar in some ways to the tools used in previous studies when measuring patient satisfaction with care in hospitals [5, 13, 14, 28–31].

It is not easy to compare the NSS-8 with other instruments of interest, given the aim of the instruments and the different populations. However, some parallels are found between the NSS-8 and other instruments used in similar populations. Bjertnaes et al. (2012) found that the most important predictor for adult patient satisfaction with hospitals in Norway (N63) was the quality of nursing services [29]. Weiss et al. (2009) showed that giving awareness and informing about care and treatment after discharge and paying attention to the parents' needs for what they want increase their satisfaction with hospital services [32]. Because nurses are probably the most important care providers in hospitals, there should be emphasis on nursing-service quality as one of the determining factors of parents' satisfaction.

Other studies found a significant relationship between nursing courtesy, respect, careful listening, easy access of care, work environment, and patient-nurse staffing ratio and satisfaction with hospital stay [9, 33–37].

In the present study, the first factor of the questionnaire "Care and Treatment" encompasses items on emotional support, care, assessment when admitted in the unit, and many questions about the nurses. Support from staff is widely recognized as an important factor in measuring satisfaction with health care. The same theme was found by Rafiey et al. (2016) in their survey [38]. It is important for parents to experience a high level of support when admitted to the NICU, and we assume that it will also have a positive influence on their satisfaction with their stay in NICU. Hagen et al. (2015) found that one of the most important factors for the parents' coping experiences in the NICU was positively influenced when health personnel listened to the parents' needs and opinions regarding their infant [39]. In our survey, we have items covering this part such as "To what extent did you experience that the care personnel signalled that they had time for you" and "were interested in hearing your opinions as a next of kin". Similar questions were also found in a Canadian survey [30].

The second factor in our survey is "Doctors". We can see that some studies also separate doctor's care from nurse's care [29, 38], and other studies measure them in the same factor [13, 14, 38]. In Scandinavian hospitals, the nurses are important for the patients and next of kin when measuring satisfaction with care in NICU. Our study showed that satisfaction related to the nurses' care was the most important, whereas the doctors' care was ranked on the 4th place (Table 6). These results concurred with those present in other studies in general in Europe [29, 33]. In a Chinese study, doctors ranked first [28].

The third factor was “Visit”. This factor covers items of visit conditions and routines in the unit. In other surveys, we could not find similar items referred to visit. One study from Georgia reported that visit from the infant’s siblings was ranked as one of the least important needs of families of patients in NICUs [40]. In the present survey based on Scandinavian culture, visiting from the infants’ siblings and next of kin is important and was ranked as number three in our satisfaction rate (Table 6).

The fourth factor was “Information”. Receiving good, understandable, and sufficient information is ranked high when measuring quality of health care in hospitals [41, 42]. Schoenfelder et al. found that information did not have a major influence on patient satisfaction [33], but he was exploring patients in hospital, not parents to new-born infant in NICU. The information needs can be different in different settings. Sawyer et al. (2013) identified four key dimensions important when measuring quality in NICU when a premature infant is born: information, explanation, encouragement, and listening to parents with empathy. They included a dimension of information and explanation in their survey covering seven items [14]. We have also covered similar questions in our survey, both in this dimension and spread in some of the others.

The fifth factor is the “Unit Facilities” including both facilities for parents and privacy (patient and next of kin’s physical space in order to avoid intrusive atmosphere and to ensure confidentiality for parents and infants). Questions on facilities were also found in one instrument [28] but were among the least important needs of families of patients in NICUs from both USA and China [28, 40].

The sixth factor is about parent anxiety and two of the four items are also taken from the Groven questionnaire [43]. The remaining two items came from the development of NSS-13 [18]. These questions were important for measuring parent satisfaction when admitted to the NICU; but in Mundy’s study, these items were not regarded as important [40].

Questions about discharge were the seventh factor in our survey, covering three items of receiving necessary information and being prepared to manage the necessary follow-up care of the child after discharge from the NICU. Preparing for discharge was just highlighted in one other study when measuring quality in health care [5].

Questions about siblings were the final factor covering health personnel offering attention to the siblings’ needs and their reaction to parents living in the NICU. This dimension was not found in other studies. Because the hospitalization of a child in NICU will influence the whole family, we consider siblings to be an important aspect to take into account in the questionnaire. The Norwegian government recommends that, if the admitted child has siblings, the unit should provide suitable

facilities for them to visit [44]. The clinical implications of this study could help NICUs to monitor parents’ satisfaction and dissatisfaction. NICUs in the western world have much in common. The NSS-8 is designed to measure eight areas associated with satisfaction in NICUs. The different NICUs should compare their structure in order to see if the NSS-8 is suitable in their units. Due to the similarities of NICUs in Scandinavia the generalizability is probable.

Limitations and strengths

Parents in our study answered the questionnaire while still in the NICU, and they reported overall high satisfaction with their stay. Parents may have felt reluctant to criticize the professionals who had taken care of them and their infant which might have contributed to a bias in questionnaire returns. However, there are reported factors such as long and short perinatal stay, instrumental operative delivery, unexpected medical problems, multiple physical symptoms, and complicated perinatal course that need to be related to dissatisfaction [45]. A longitudinal approach could have been better. Measuring expectations and satisfaction also some time after discharge could have provided a better insight into this phenomenon.

Secondly, the criterion validity using a “gold standard” was not tested. Few validated parent-satisfaction instruments are developed after family-centred care was implemented in NICUs, and we therefore consider “gold standards” not important in our study.

The third limitation is the response rate in this study. The respondents represent 45% of the population but response rate is considerably higher due to the following explanations, but is higher than average for Norwegian national patient-experience surveys [29]. The lack of data from refugees not speaking any of the Scandinavian languages or conversant with English, was a feature of the survey period, during which parents from Syria formed a notable group. A number of responses were not collected due to administrative errors. The absence of men/fathers during the period of their child’s admission to the NICU is also a consideration. Another reason could be that we had no follow-up or reminder to answer the survey. In our study, 568 parents answered the survey (45%), and this is a large number of respondents from a wide geographical area in Norway. This will also give statistical power and protect from bias. To protect from selection bias, we tested possible differences between the responding and non-responding groups and found no differences in GA and length of stay. However, we cannot predict how the non-responding group would have answered the survey.

Test-retest reliability can assess the stability of a measure over time and is recommended in the process of any questionnaire development. This is of particular importance if the intended use of the measure is to assess change

over time or when current mood states are not likely to remain stable over a period of a few weeks.

Finally, we have not considered the possibility of biased sample when both parents have responded to the questionnaire.

The level of missing data is low (mean 1.1%) for the final survey, which suggests that it is acceptable to respondents.

To our knowledge, this survey seems to be the only tool designed for measuring parent satisfaction in NICUs in Scandinavian countries based both on Norwegian/Scandinavian recommendations for measuring quality in health care in hospitals and on experts on health personnel and parents of patients admitted to a NICU.

The NSS-8 is translated to English and is easy to score. The sample size was relatively high for factor analysis, which strengthens the validation process of the questionnaire.

This survey is based on both mother and father, and many fathers participated in the study (45%). This is a strength because studies suggest that the fathers' experiences with care in NICU differ from those of the mothers [46]. This could therefore influence the fathers' evaluation of care. Fathers of sick, preterm babies are recognized as a difficult group to recruit for research [47].

Conclusion

The NSS-8 is a parent-completed survey questionnaire which explores several key aspects of their experiences with NICU. The final 51 questions give good evidence for face and content validity and include important aspects of care in NICU.

The NSS-8 questionnaire is a valid and reliable scale for measuring parent satisfaction with developmental care in NICU. The parent-satisfaction outcomes might contribute to identify interventions to improve the quality of care in NICU and can be used fully or only through a few of the factors. We are confident that NSS-8 will generate insights into different aspects of quality of care, especially in areas where there is a need for improvement, but also to provide an understanding of what is perceived as being done well. We recommend researchers in different countries to further validate the NSS-8.

Abbreviations

GA: Gestation age; NICU: Neonatal Intensive Care Unit; NSS-13: Neonatal Satisfaction Survey 13; NSS-8: Neonatal Satisfaction Survey 8

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Availability of data and materials

The data used in the current study is available from the corresponding author on reasonable request.

Authors' contributions

IHH, design, data collection, transcription, analysis, interpretation of data; MFS, drafting the manuscript and revising it critically for important intellectual content, writing assistance, and analysis; VCI, drafting the manuscript and revising it critically for important intellectual content; EN, data analysis; RO, drafting the manuscript and revising it critically for important intellectual content. All authors have read and approved the study.

Ethics approval and consent to participate

Permission to conduct the study was obtained from Regional Committees for Medical and Health Research Ethics in Norway (Ethics Reference Number 2015/386) REK nord). Signed informed consent was obtained from each participant before they participated in the study. Participants were informed of their rights to withdraw from the study at any time. Anonymity of participants was maintained and assurance given that all information would be treated in absolute confidence. Participants were also provided with written information sheet on the study and their rights regarding participation and the option of withdrawing at any time.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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Paper III

RESEARCH ARTICLE

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Parental satisfaction with neonatal intensive care units: a quantitative cross-sectional study

Inger Hilde Hagen^{1*}, Valentina Cabral Iversen^{2,3}, Erik Nasset¹, Roderick Orner⁴ and Marit Følsvik Svindseth¹

Abstract

Background: Patients and users experiences are useful for monitoring the quality of the hospital provisions and to improve health care delivery. Research results on associations between parental satisfaction and their socio-demographic status are inconclusive. We have also found a scarcity of research on the associations between parental satisfaction and standards of neonatal intensive care (NICU) services. We used the Neonatal Satisfaction Survey (NSS-8) to collect data to explore associations between parental satisfaction and socio-demographic variables and, associations between parents' satisfaction and NICU care-services.

Methods: A total of 568 parents from six different NICUs geographically dispersed in Norway completed the (NSS-8). All responses were rated and analysed using nonparametric analyses and logistic regression.

Results: Support from families and friends is the most important sociodemographic area which links to reported levels of parental satisfaction. The most important areas for parents' satisfaction with NICU care services include the decision making processes regarding the infant, respect and empathy from staff, and the continuity of treatment and care. Parents were least satisfied with how NICUs facilitate ongoing care for siblings, parents and infants during later stages of their hospital stay. Parents reported being in need of more guidance and training in meeting their child's needs.

Conclusion: To increase and sustain parents' satisfaction with NICU care considerations should be given to separate elements of the total provision made for affected families. This study suggests that health personnel could address the needs of all family members as these evolve through phases of their stays in hospitals; be more attentive to parents with very preterm infants and parents with long NICU admissions; provide support to siblings; and give more attention to parents' needs for continuity of care, follow-up, and information.

Keywords: NICU, Parents, Satisfaction, Family-centred care

Background

Patient and next of kin satisfaction surveys are an important and frequently used part of measuring the quality of health care [1, 2]. Parental experience is a crucial measure of service quality from the patients and parents' perspective, and contributes to their overall satisfaction [3, 4]. These experiences might be useful for monitoring the quality of care in hospital wards and could point to ways of improving health care delivery [5].

The birth of an infant is challenging for all parents. Intense emotions and stress are particularly acute when an infant is born prematurely or with health problems and admitted to a neonatal intensive care unit (NICU). Parental stress is related to worries over the infant's health, the infant's outcome, and alterations to the parenting role, and feelings of grief concerning the loss of a fully healthy child are common [6–9]. Rocha et al. (2011) found that parents with a high level of stress are less satisfied with the care of the doctors. Additionally, mothers with high level of stress are satisfied with the attendance of the nursing team [10]. Studies show significant associations between parental satisfaction with health care in

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NICUs and their ability to give appropriate care for their child [11, 12]. Generally, higher satisfaction with health care is reported to yield better treatment compliance [1].

Family-centred care (FCC), defined as “[...] an interdisciplinary, comprehensive, and holistic care of neonates and families with maintaining their respect and dignity” ([13], p272), is necessary to promote the quality of NICU care. FCC is considered the gold-standard medical concept in the NICU [13] and is implemented in most units in the western world, but varies between countries and units. However, research shows that there still is a way to go before it has been rooted [14]. Evaluating parent satisfaction is important in NICU settings, and validated instruments based on FCC principles are recommended [13]. Research shows that FCC reduces stress and anxiety among parents [11, 15] and increases parental satisfaction by giving them the opportunity to participate in the child’s health [16].

A variety of factors are crucial when measuring satisfaction and quality of health care in NICUs. In a study from California, McCormick et al. (2008) measured mothers’ satisfaction and found that the main predictor of satisfaction with NICU care is the child’s health at the time of the interview. They also found that mothers’ education level, age, and ethnicity are significant predictors of satisfaction. Older, more educated, and white mothers were more satisfied with health care compared to non-white mothers and those with lower family income [17]. In contrast, a study from Canada revealed that mothers’ age and education level are not significantly associated with satisfaction scores [18]. Tsironi (2012) found that parents’ gender and duration of infants’ hospitalization are the most significant factors for parental satisfaction [19]. In their review, Butt et al. (2013) found that few studies have been performed to measure the factors related to parental satisfaction with NICU care, coinciding with the limited consensus over which parental or child demographic variables are correlated with satisfaction [20]. There is growing evidence that support from other NICU-parents and staff are important for parents and that organized support from peer-to-peer and NICU staff has been beneficial [21, 22]. There is, however, scant research on what support from family and friends means for parents.

The relationships between health personnel and patients are key factors in a parent’s satisfaction with care in NICU. Parents need information, continuity of care and health personnel listening to their needs [5, 23, 24]. Improving quality necessitates gathering data both from the parents’ experiences with different factors as well as the level of satisfaction with each factor [25].

The literature identifies a need for more research on which socio-demographic variables are associated with patient satisfaction and factors important for parents

being satisfied with the neonatal health care services, including factors related to patient-reported experiences. This study can contribute to new knowledge about the factors that have an impact on satisfaction and give recommendations of how to improve health care services to increase parents’ satisfaction. Thus, this study aims to investigate:

- a) Associations between parental satisfaction and socio-demographic variables.
- b) Associations between parental satisfaction and neonatal intensive care services

Methods

A multicentre prospective cohort study was conducted between September 2015 and October 2016. The design of the study is nearly similar to the design of a former study using the same data set [26]. However, there were some minor differences compared to Hagen et al. (2018) because other variables were tested in this study. In the former study, we aimed to statistically validate the Neonatal Satisfaction Survey (NSS-13), which included 67 questions, in six geographically spread Norwegian NICUs, and we estimated that a total of 450 answered questionnaires were necessary for a proper factor analysis. Therefore, we wanted each unit to collect approximately 100 completed questionnaires. From the factor analysis, a new questionnaire (NSS-8) was developed including 51 questions. Compared to NSS-13 there was a reduction in the number of questions.

Study population and sampling strategy

Participants were Norwegian or English-speaking parents admitted to one of the six NICUs whose admissions lasted for more than two days to have a time basis for expressing their views. The infants’ gestation ages ranged from 24 to 42 weeks. The NICUs also admitted infants up to 3 months after birth. Parents whose children died while in the unit were excluded from this study. Our goal was to provide enough data to perform proper statistical analysis to validate the NSS-8. Due to reports from nurses collecting data, the parents that did not answer the survey were lost mostly due to administrative reasons and exclusion criteria, and we concluded that our sample was probably representative.

The first author contacted the head of the clinic in 12 NICUs and asked them to participate in the study. All the NICUs were organized quite similarly and shared the same philosophy of treatment and care. Due to the number of participants volunteering to participate and the fact that these hospitals also represent all geographical areas in Norway, we decided not to pursue contact with the six hospitals that did not answer the call for participation. The recruitment process followed a strategic selection

according to the inclusion criteria. Participating NICUs varied in size from 6 to 21 beds (mean 12.5) and treated between 253 and 500 patients each year. Two NICUs are university hospitals, and the rest have regional or local catchment areas. Three units treated children of gestation age (GA) ≤ 23 , while the rest provided care for children from GA 26–30.

Data collection methods

The first author introduced the study to the unit nurses. Three research assistants in each hospital were responsible for questionnaire distribution and collection. During the data collection, the first author maintained regular contact with the research assistants via telephone and email. Some units were also visited during the data collection process. Research assistants in the participating NICUs identified parents who were eligible study participants. As discharge approached, the research assistant contacted the infants' next of kin to secure their informed consent to take part in this study. The research assistant left a copy of the self-reported questionnaire with participating parents a few days before discharge from the unit. Parents with multiple births received only one questionnaire. To ensure confidentiality, parents dropped their completed survey form in a secured box at the unit.

Measures

Socio-demographics

Mothers and fathers answered questions on demographic variables, such as age, level of education, native language, main income, civil status, and driving distance from home to hospital. Parents were also asked about their infant's gestation age, number of children, and support from family and friends.

A *Neonatal Satisfaction Survey (NSS-8)* covering family-centred care principles [13, 14, 27] was used to gauge parental satisfaction with care-services provided within NICUs. The NSS-8 questionnaire contains 51 items and two overall satisfaction questions developed from literature reviews, focus group interviews with health personnel and parents of children in a neonatal unit. A pilot study was conducted [28]. Further validation was completed, and eight factors were extracted based on a principle component analysis of the 568 respondents [26]. These factors cover aspects related to *care and treatment*, *doctors, visits* (conditions, routines), *NICU facility*, *siblings* (facilitating for siblings), *information, parent anxiety*, and *discharge*. Cronbach's alpha was calculated in the validation study [26] and varied between 0.70–0.94 for the eight factors. The factors are all validated and more thoroughly described in Hagen et al. (2018). The various questionnaire items were measured by a Likert scale with 5 alternatives. The NSS-8 is suitable for measuring parents'

overall satisfaction as well as their experiences in eight spheres of care. The questionnaire was translated from Norwegian to English and back to Norwegian.

Ethics

The study was conducted according to the Helsinki Declaration. This project was first presented to the Regional Committees for Medical and Health Research Ethics, which reported that permission to conduct the project was not necessary (2015/386). The project was approved by the Norwegian Data Protection Authority. After having read an information letter concerning the study, all respondents were asked for oral and written consent to participate. We emphasized that participation was voluntary and that parents could withdraw from the study at any time.

Analyses

The internal consistency of the NSS-8 was assessed in the main study using Cronbach's α and item-total correlations of all 51 questions in NSS-8 [26]. Descriptive statistics, including frequencies and percentages, are shown for all eight NSS-8 factors and the socio-demographic variables. Continuous data were transformed into categorical data presented in descriptive statistics. Because data were strongly skewed (towards high satisfaction), nonparametric methods compared overall satisfaction scores and demographics, support, and single items in the NSS-8, as reported with descriptive values (median, range, mean, SD). Chi-square tests were used for analyses of associations between variables. The relationships among the eight factors of perceived satisfaction with care, demographic data, and support were investigated using Spearman's rank correlations coefficient.

Because of the skewed dataset and to present our results in a readable crosstable, a nonparametric test was used, and the variables in NSS-8 were therefore dichotomized according to clinical decisions. The cut-off on the five-point Likert scale was set between those scoring "not at all", "small degree", and "some degree" of satisfaction (low satisfaction) and those scoring "largely" and a "very large extent" (high satisfaction). NSS-8 measures the degree of parental satisfaction with NICU health care-services. For the variable "stress, unrest and insomnia", the cut-off was set to "not at all" to "in small degree" (low stress) and those scoring "some degree" to "very large extent" (high stress).

The two overall questions, *satisfaction with infant treatment* and *satisfaction with parent treatment* were dichotomized as follows: items 1–3 (very dissatisfied, quite dissatisfied, and neither satisfied or dissatisfied) were classified as "low satisfaction". Items 4–5 (quite satisfied and very satisfied) were classified as "high satisfaction". These two variables and selected dichotomized

variables from the NSS-8 questionnaire were then cross tabulated.

Logistic regression was performed to assess the association between socio-demographic variables and support and the likelihood that respondents would report satisfaction with care. The dependent variable is a dichotomized version of the average of the 51 questions dealing with the different aspects of satisfaction, where (after clinical assessment) values from 1 to 4.1961 (the median value) were labelled as “low satisfaction” and values higher than 4.1961 as “high satisfaction”. The independent variables were categorical but the age of the parents was continuous in order to not lose power.

The questionnaire responses skewed markedly towards parents who were satisfied with NICUs. Aspects of care-services to be improved were difficult to establish by statistical means. Therefore, we decided to describe the areas where more than 10% (cut-off: $N \geq 14$) of the respondents reported dissatisfaction with the NICU, given that they also reported dissatisfaction with the stay in the NICU in the overall question (Table 6). The 10% cut-off was used to exclude incidental responses, and on a desire to refrain from overanalysing dissatisfaction reports in such a skewed material. A two-tailed p -value less than 0.05 was considered statistically significant. All analyses were conducted via SPSS 25.

Results

Descriptive analyses

The response rate for the six participating hospitals varied from 33 to 66%, and the mean was 45%. Attrition analysis found that there were no differences between the non-responders families ($n = 722$) from those responding ($n = 325$) regarding the infant's gestational age or length of stay, as shown in a table in a previous article [26]. The level of missing data in the completed forms was low (mean 1.1%), suggesting that the NSS-8 questionnaire is understandable and easy to answer.

Table 1 shows the descriptive statistics of the eight NSS-8 factors and selected background and socio-demographic variables. All eight factors had high mean scores, which is quite normal in such analyses. Of the 568 parents that completed the questionnaire, 312 (54%) were mothers and 256 (45%) were fathers. The mean age in the sample was 30 years of the mothers (SD 5.50) and 33 years for the fathers (SD 6.94). There was a significant difference in education between mothers and fathers ($p = 0.013$), where 184 mothers (59%) had a higher education (≥ 4 years) compared to 116 fathers (46%), and 95 mothers (30%) were undergoing unpaid work/education versus 24 fathers (9%).

A total of 275 (88%) mothers reported receiving support from family and friends compared to 232 fathers (91%). A total of 124 mothers (40%) reported being

alone with the infant in the NICU versus 25 fathers (10%). Most of the parents were Norwegian ($N = 275$, 88% mothers; 232, 91% fathers), and the length of the NICU stay ranged from two days to two weeks (median = 2 weeks; SD, 1.078). Most of the parents (532, 94%) characterized their child's health as good, while 22 (4%) characterized their child's health as poor (Table 1).

Of the 352 infants in the study, 245 (70%) were born with $GA \leq 37$. There were 29 couples with twins (Table 2).

Parental satisfaction items were skewed towards positive assessment (mean 4.15, SD .46) on a scale of 1–5, where 5 represents the most positive score. A total of 432 (76%) were highly satisfied with NICUs, answering from “largely” to “a very large extent”. For the two overall questions, we gathered a total score for the parent's satisfaction with the care of the infant. In the first question, 99% reported satisfaction; in the second question (parents' satisfaction with other elements of care), 91% of the parents reported satisfaction.

Cronbach's alpha for the eight factors in NSS-8 was the same as in our previous article as follows: factor 1; *care and treatment* 0.94, factor 2; *doctors* 0.91, factor 3; *visits* 0.91, factor 4; *information* 0.81, factor 5; *facility* 0.72, factor 6; *parental anxiety* 0.74, factor 7; *discharge* 0.70, and factor 8; *siblings* 0.72. The item-total correlation was 0.95. Corrected item-total correlation showed that none of the single items in the questionnaire was higher than the item-total correlation, which indicates that each item correlates well with the total score [26].

Correlations between NSS-8 factors and demographics and support

In the correlation matrix (Table 3), there were small to moderate significant correlations between seven out of thirteen independent areas (gender, education level, duration of stay, support, infants' health, GA, and single/multiple birth) and the eight NSS-8 factors. Parents' age, language, main income, travel time, civil status, and sole providers were not statistically correlated with any of the eight NSS-8 factors. Mothers were more anxious compared to fathers and parents' education level was negatively correlated with *doctors*, indicating that those with less education were more likely to be satisfied with NICU doctors. The duration of stay showed a significantly negative correlation with *doctors*, *facility*, and *parental anxiety*. In other words, a longer duration in the NICU decreased satisfaction with *doctors* and the *facility* and increases anxiety.

Receiving support from family and friends and infants' health were the area's most important for satisfaction level. A higher level of support increased the satisfaction level and decreased parents' anxiety. Infants' health was significantly and positively correlated with all eight

Table 1 Descriptive statistics: NSS-8 factors and sociodemographic variables, parents (*)

	N	Median (Range)	MEAN (SD)
Factors in NSS-8			
F1 Care and treatment (1–5)	493	4.6 (2.0–5.0)	4.5 (0.5)
F2 Doctors (1–5)	547	4.1 (1.0–5.0)	4.0 (0.7)
F3 Visit (1–5)	543	4.3 (1.3–5.0)	4.4 (0.7)
F4 Information (1–5)	526	4.3 (1.0–5.0)	4.2 (0.7)
F5 Facility (1–5)	512	4.5 (1.8–5.0)	4.4 (0.6)
F6 Parent anxiety (1–5)	562	4.0 (1.0–5.0)	3.8 (0.9)
F7 Discharge (1–5)	549	4.0 (1.7–5.0)	4.0 (0.8)
F8 Siblings (1–5)	171	4.0 (1.0–5.0)	3.7 (1.1)
Total satisfaction of NSS-8	432 (76%)		
Demographic Variables			
Mother's age	312	29 (18–42)	30.1 (5.5)
Father's age	256	32 (19–62)	33.1 (7.0)
	N (%)		
Education level mothers:			
Higher ed. > 4 years	76 (24)		
Higher ed. < 4 years	108 (35)		
College	113 (36)		
Grammar school	15 (5)		
Education level fathers:			
Higher ed. > 4 years	50 (20)		
Higher ed. < 4 years	66 (26)		
College	126 (50)		
Grammar school	12 (4)		
Work status mothers:			
In paid work	217 (70)		
Not paid work/education	95 (30)		
Work status fathers:			
In paid work	232 (91)		
Not paid work/education	24 (9)		
Main income mothers:			
In paid work	233 (75)		
Not in paid work	79 (25)		
Main income fathers:			
In paid work	236 (92)		
Not in paid work	20 (8)		
Marital status mothers:			
Married/in relationship	300 (96)		
Divorced/single parent	11 (4)		
Marital status fathers:			
Married/in relationship	247 (97)		
Divorced/single parent	7 (3)		
Language mothers:			

Table 1 Descriptive statistics: NSS-8 factors and sociodemographic variables, parents (*) (Continued)

	N	Median (Range)	MEAN (SD)
Norwegian	275 (88)		
Not Norwegian	37 (12)		
Language fathers:			
Norwegian	232 (91)		
Not Norwegian	24 (9)		
Travel time to hospital mothers:			
Less than 1 h	156 (50)		
More than 1 h	156 (50)		
Travel time to hospital fathers:			
Less than 1 h	137 (54)		
More than 1 h	119 (46)		
Length of stay			
2 days – 2 weeks	347 (61)		
> 2 weeks	221 (39)		
Sole provider mothers:			
Yes	124 (40)		
No	188 (60)		
Sole provider fathers:			
Yes	25 (10)		
No	231 (90)		
Support from family and friends mothers:			
Support	275 (88)		
Not support	37 (12)		
Support from family and friends fathers:			
Support	232 (91)		
Not support	24 (9)		

Median and range reported as appropriate for non-parametric data and Mean and SD are reported as additional data information

(*) Partly reported in Hagen [26] due to same data collection

factors, indicating that better infant health led to greater satisfaction with the NICU and less parental anxiety.

Parental satisfaction with the factors *care and treatment*, *doctors*, *facility*, and *visits* in NICU increased with higher GA. Parental anxiety indicated that the later gestation, the less fear among parents concerning the infant, although the effect size was very small (16%). Single or multiple birth was significantly and negatively correlated with the factors *doctors* and *visits*.

Associations between total satisfaction (NSS-8) and socio-demographics and support

The logistic model that included all independent variables showed a significant improvement compared to the base model with only the constant term, as indicated by the chi-square test of the change in log-likelihood (χ^2 (13, $N = 568$) = 65.356, $p < 0.01$). According to Table 4,

Table 2 Demographics of the parents' infant (N = 352) participating in the study. (a)

Variables	Total (%)
Was your child premature or born at term?	
Premature (< 37 weeks)	245 (70)
Born at term (≥ 37)	107 (29)
Multiple birth	29 (1.0)
Parents' evaluation of the child's health (N = 568)	
Good	532 (94)
Poor	22 (4)
Missing	14 (2)

(a) Partly reported in Hagen [26] due to same data collection

the model explained between 15% (Cox and Snell R square) and 20% (Nagelkerke R squared) of the variance in satisfaction status. Our model showed an overall classification accuracy rate of 65.7%, which is more than 25% higher than the proportional-by-chance accuracy rate of 50%.

Parents' age, education level, support from friends and family, infants' health and infants' GA made a unique statistically significant contribution to the model. The most important area was support from family and friends. The model indicated that a parent with support from family and friends has an odds of being satisfied with the NICU that is 2.4 times that of a parent with no such support. The second most important area was infant gestation age. A Parent to an infant born at term has an odds of being satisfied that is 1.4 times that of a parent to an infant born extremely premature. The third most important area is parents' age. Older parents has an odds of being satisfied that is 1.07 times higher compared to younger parents. A parent reporting good

infant health has an odds of being satisfied that is only 0.57 times that of a parent reporting bad infant health. Finally, a parent with primary or high school has an odds of being satisfied that is 0.52 times that of a parent with college or university education (controlling for all other factors in the model).

Associations between parental satisfaction and neonatal intensive care services

Parents who had one doctor with the principal responsibility for the child were significantly more satisfied with the NICU than those not experiencing such continuity. The same was found with parents reporting a permanent group of caregivers looking after the infant compared to those not experiencing continuous support. Those reporting that care personnel had time for parents were also significantly more satisfied with NICU. Similarly, perceiving respect and understanding from health personnel led to significantly greater satisfaction (Table 5).

There were also significant associations between parents reporting the perceived consideration and care from nurses and doctors and satisfaction with care. Moreover, there was a significantly positive association between satisfaction and having health personnel who were interested in listening to parents' opinions on treatment and care for the infant.

Finally, questions about parental stress, unrest, and insomnia in connection with the NICU stay had a mean score of 3.5 (SD 1.1), indicating a large degree of perceived stress. We therefore wanted to investigate if perceived stress was associated with parental satisfaction for the entire NSS-8, which was not significant.

Table 3 Significant Spearman's rank correlations^a between NSS-8 and demographic data, support and child's health. Total N = 568

Demographic	Care and treatment	Doctors	Facilities	Information	Visit	Parents anxiety	Discharge	Siblings
Gender						.100*		
Parent age								
Language								
Education level		-.090*						
Main income								
Marital status								
Travel time								
Duration of stay		-.102*	-.213**				-.257**	
Sole provider								
Support from family and friends	.338**	.268**	.128**	.303**	.242**	.119**	.249**	
Infant health	.195**	.121**	.157**	.134**	.138**	.318**	.227**	.180*
Gestation age	.100*	.154**	.268**		.109*	.162**		
Single or multiple birth		-.112**			-.087*			

*: $p \leq 0.05$, **: $p \leq 0.01$ (2-tailed)

^aNon-significant correlations are excluded

Table 4 Logistic regression predicting likelihood of reporting high and low satisfaction with NICU

	B	S.E.	Wald	P	Odds ratio
Gender	-.293	.258	1.287	.257	.746
Parent age	.065	.020	10.158	.001	1.067
Language	-.355	.464	.584	.445	.702
Education level	-.646	.234	7.620	.006	.524
Main income	-.261	.301	.749	.387	.771
Marital status	-.836	.717	1.361	.243	.433
Travel time	-.062	.090	.485	.486	.940
Duration of stay	-.074	.155	.230	.632	.929
Sole provider	-.308	.278	1.223	.269	.735
Support	.867	.174	24.681	< 0.001	2.379
Infant health	-.560	.279	4.014	.045	.571
GA	.327	.158	4.258	.039	1.387
Single or multiple birth	-.381	.401	.901	.342	.683
Constant	-5.670	1.287	19.414	.000	.003

Cox and Snell R square 15%, Nagelkerke R squared 20%
 X^2 (13, N = 568) = 65.356, $p < 0.01$

Table 6 shows the distribution of respondents who reported dissatisfaction with NICU care-services and questions with the highest frequency of dissatisfaction. Parents were most dissatisfied with how NICUs are prepared for the infants' siblings. Improvements were also needed in the following areas: continuity of care, information, and follow-up.

Discussion

We conducted a cross-sectional study to investigate associations between parental satisfaction and socio-demographic variables and, associations between parents' satisfaction and neonatal intensive care-services.

Most parents reported moderate to high levels of satisfaction with NICUs (76%). High satisfaction levels were also observed internationally [17, 20, 24] and in other health care units in Norway and in comparable countries [29, 30]. FCC is the standard in NICUs, and parents are encouraged to spend more time with their infants and to participate in their care. Research has shown that FCC can contribute to improving satisfaction and reducing distress among parents [31, 32].

Regarding socio-demographic variables, the study found that support from families and friends, followed by infants' gestation age, parents' age, infant health, and parents' education level were the most important areas for satisfaction.

Except for the factor *siblings*, support from family and friends was statistically positive and significantly associated with all NSS-8 factors. The regression model also unearthed support as the most crucial question, indicating that when controlling for all other demographic

questions in the model, parents receiving support from family and friends were 2.4 times more satisfied as a whole with the NICU than those lacking support. To our knowledge, no other studies have explored the association between satisfaction with the NICU and support from family and friends. One study, however, explored patient satisfaction with the health-care system and concluded that patient satisfaction depends more on areas external to the health system compared to the experience of care as a patient [29]. Some studies have pointed to family and friend involvement as a coping strategy [33, 34], which is consistent with FCC principles [35].

In our study, infants' gestation age was significantly and positively related to five of the eight NSS-8 factors, indicating that the closer to term the baby is born, the more satisfied parents. Our regression analysis also indicated that gestation age was the second most important variable when controlling for all other demographic questions. One study from the USA found that parents of infants with a gestational age ≤ 32 weeks were significantly more likely to report feeling confused compared to parents of less premature infants [36]. Confusion and lack of control can often lead to dissatisfaction. However, a previous review study did not find similar correlations, and report ambiguous findings when comparing birth weights and satisfaction [20].

Parents' age was not significant for any of the eight factors in our correlation matrix. Nevertheless, we found that parents' age was the third most important areas and was positively and significantly related to total satisfaction with NICU, indicating that older parents were more satisfied. This result is consistent with one other study [17], although this association was not reported in other studies. Wong et al. (2011) found that age was not significantly related to parental satisfaction, while Tsironi et al. (2011) found that younger parents were significantly more satisfied than older parents were.

In our study, education level emerged as negatively and significantly related to satisfaction with one of the NSS-8 factors, namely *doctors*. The regression analysis also revealed a negative and significant relation to the total score of satisfaction, indicating that those with lower education were more satisfied with the NICU. This result is consistent with Tsironi's study [19], who also found that parents with basic education expressed a higher level of satisfaction, possibly explained by their lower expectations and demands from the health care system. A Canadian study found no association between parental education level and parental satisfaction [18].

For all NSS-8 factors in the correlation matrix, infant health as rated by the parents was also negatively and statistically associated with parental satisfaction. The regression model revealed that parents of infants in good health were more satisfied with the NICU compared to

Table 5 Associations between perceived high and low satisfaction and some of the clinical interesting items from NSS-8

	Overall question about parents satisfaction with care of the infant		p	ES (Phi)
	Low satisfaction N (%)	High satisfaction N (%)		
One doctor responsible (N559)				
Low degree	30 (77)	307 (59)	.042	.09
High degree	9 (23)	213 (41)		
Overall question about parent satisfaction with care of parents				
	Low satisfaction N (%)	High satisfaction N (%)	p	ES (Phi)
Continuity of care (N564)				
Low degree	22 (46)	135 (26)	.006	.12
High degree	26 (54)	381 (74)		
Care personnel signaled that they had time for parents (N560)				
Low degree	16 (33)	25 (5)	< 0.001	.31
High degree	32 (67)	487 (95)		
Personnel showed understanding and respect for parents situation (N562)				
Low degree	15 (31)	22 (4)	< 0.001	.30
High degree	33 (69)	492 (96)		
Consideration and care from nurses (N561)				
Low degree	21 (44)	59 (11)	< 0.001	.26
High degree	27 (56)	451 (88)		
Consideration and care from doctors (N556)				
Low degree	27 (57)	150 (29)	< 0.001	.17
High degree	20 (43)	359 (71)		
Care personnel were interested in hearing your opinions as parents (N560)				
Low degree	16 (33)	61 (12)	< 0.001	.17
High degree	32 (68)	451 (88)		
Doctors were interested in hearing your opinions as parents (N557)				
Low degree	23 (48)	131 (26)	.002	.14
High degree	25 (52)	378 (74)		
Stress (N560)				
Low degree	19 (40)	263 (51)		
High degree	29 (60)	249 (49)	.16	.07

Effect size (Phi) = small effect = .10, medium = .30 and large = .50

those who did not rate their infant's health as good. A previous study found that the major predictor of parental satisfaction with neonatal intensive care was infant health at the time of the interview [17]. A review article found little consensus between satisfaction with the NICU and infant or parental demographic variables [20]. Similar to our study, however, they found that some studies pointed to a positive association between satisfaction ratings and parental perceptions of their infant's health.

The amount of variance explained by the variables in our study was small, although this is similar to other studies [17]. On the other hand, support from family

and friends explained the largest share of variance in satisfaction. The implications for praxis is that health personnel, when caring for parents who lack good relations with family and friends, must keep in mind the strong and positive association between parental satisfaction and support from family and friends.

Being a parent to a premature or sick newborn infant who is admitted to the NICU is well documented as a stressful event [7, 9, 37]. We found no significant relationship between perceived stress and satisfaction. A Portuguese study found that mothers' stress levels increased when they were not satisfied with doctors [10], although cultural differences can make comparability

Table 6 Potential for improvement: Parents' perception of dissatisfaction with NICUs services. N 136

N	Questions from NSS-8
Overall question about parents satisfaction with care of the infant	
30	To what extent did you experience that one doctor had the principal responsibility for the child?
Overall question of parents satisfaction with their one care	
35	To what extent were the siblings' reactions paid attention to?
35	To what extent are you satisfied with the activities offered to the child's siblings?
29	To what extent did you experience stress/anxiety/sleeplessness in connection with the stay at the unit?
28	During the child's admission, do you think you were given the necessary information about the effects and side effects of new medication given to the child?
27	To what degree do you think the doctors showed care and consideration for the child?
26	Have you been given information about what to do if the child become ill/have a relapsed/need medical attention after returning home?
25	To what degree do you think the doctors signaled that they had time for you?
24	While the child were admitted, were you at any time afraid that the child would have delayed injury/after-effects?
23	To what extent did you experience that the care personnel provided relief or assistance to the admitted child during the stay?
23	To what degree do you think the doctors were interested in hearing your opinions as next of kin?
22	To what extent did you experience that you were taken care of later in the process?
21	To what degree do you think the doctors appeared professionally competent?
21	To what extent did you experience that the care personnel had consideration and care for you?
17	Do you think you were given the necessary information for the period following discharge?
17	To what degree do you think the doctors gave you and your child sufficient information regarding the prognosis/outcome?
17	To what extent did you experience that you receive guidance /training in meeting your child's needs?
16	To what extent did you experience that the care personnel were interested in hearing your opinion as a next of kin?
16	To what extent did you experience that the care personnel signaled that they had time for you?
16	Were you angry, upset or disappointed in the hospital personnel during the stay?
16	Do you think you were given the necessary information about how tests and examinations were to be carried out when the child were admitted?
15	To what extent did you experience that you were taken care of upon arrival at the unit?
15	I experienced that the personnel showed understanding and respect for our situation
15	To what extent did you experience that the care personnel took your family situation into consideration?

N = those parents (> 10%) that reported low satisfaction with items and low satisfaction with overall item

between Portugal and Norway difficult. We have not found other studies investigating if satisfaction is impacted by parental stress. In our correlation matrix, gender was positively and significantly related to parental anxiety, indicating that compared to fathers, mothers were more stressed and anxious about the health and well-being of their child. Moreover, even if parents report a high level of satisfaction with the NICU, they might also experience high levels of stress at the same time. It is, however, reasonable to believe that high levels of stress may decrease tolerance to environment, which again could influence satisfaction level. Parents will worry about their child's health and well-being, and health personnel cannot always succeed in treatment, nor can they always promise that everything will be fine.

The most important areas for parents' satisfaction with NICU care-services were involvement in decision

making regarding the infant, respect and empathy from staff, and continuity of treatment and care. It is tempting to believe that if parents will be able to make decisions for the infants' treatment and care, it will be important for them to have a good relationship with the NICUs doctors and nurses. This is in consistence with a review study where they found that important areas for making decisions for their infants are the perceptions of communication and relationships with the health personnel [38].

In the present study, we also found that the relationship between health personnel and parents is an important area for parental satisfaction with NICU. We found significantly greater satisfaction among those parents who reported that one doctor had responsibility for the child, that they had one permanent group of caregivers, and when health care personnel had time for parents and conveyed respect and understanding.

Other studies have pointed out the relationship between patient and practitioner as the most important health service area affecting patient satisfaction [12, 39–45]. This emerges as a key area in parents' satisfaction with care in the NICU [5, 23, 24]. The FCC statements also highlight this relationship as important when caring for infants in hospitals [35].

Approximately one-fourth of parents in our study showed moderate to low satisfaction. However, room for improvement may be found, even when a service is regarded as good or excellent. Questionnaire responses reflect a high level of quality for the full range of NICU care-services and as such sets a baseline to aspire to. The study revealed some specific areas on which health personnel should focus. The worst performance was supporting the infants' siblings, which is an integral part of assuring high-quality services under the FCC approach in NICUs. Unfortunately, and despite the efforts made to support siblings, there are too few studies on sibling support and comprehensive services [46].

The present study, along with other studies [23, 24, 42], demonstrate that parents need health care personnel to provide consideration, information, and continuity of care during the entire period in the NICU. These findings convey that health care professionals have an opportunity to increase parental satisfaction in the NICU and help to improve outcomes.

Limitations

In the present study, parents answered the NSS-8 just before discharge from the NICU. We assume that at this time, parents are often more satisfied than they would have been earlier in the process or immediately after discharge. Just before discharge, parents probably experience a stabilized situation. They are often familiar with the health personnel; they manage to care for the infant in a familiar and safe atmosphere closely watched by NICU experts. The infant's health is acceptable or good, and the parents often look forward to taking the new family member home to the rest of the family. Hence, the timing of the NSS-8 may have skewed the results towards greater satisfaction. Furthermore, this positive bias might not be reduced when introducing the survey earlier in the NICU stay. Indeed, a positive bias might result from the possible unwillingness of respondents to answer negatively during the stay. We believe that this unwillingness is less important shortly before discharge. Using text-message questions sent to the parents mobile phones during the NICU stay [47] could be used as an alternative to a questionnaire to measure parents' satisfaction with the neonatal care and perhaps this could influence the response bias.

Another limitation is that the amount of variance explained by the study's variables was quite modest,

although this modesty was reflected in other studies [17]. Finally, the total number of admissions in the period of gathering data was 1175 new-borns. The exclusion criteria and administrative challenges were the main reasons for not answering the survey. Attrition analyses were performed for the variables *length of stay* and *gestation age*, and we found congruence between the sample and the total population. In our NSS-8 the demographic question about the infant gestation age is from 24 week to 42 week. Today it is a consensus of try to rescue infant from ≥ 23 weeks and we will change this in our next version.

Conclusions

The NSS-8 is a suitable tool for monitoring and spotting early stages of declining service standards, helping to identify specific questions that contribute to service decline.

An understanding of what is satisfying to parents would help to identify areas of caregiving in need of change and to decide which interventions to implement to further support families. In summary, this study expands the rather limited literature on areas associated with parental experiences and satisfaction during admission to the NICU. Giving birth to a preterm or sick infant is a distressing and traumatic time for most parents. Despite this, the present study suggests that parents are very satisfied with the treatment and care provided during the NICU stay. However, some elements need to be considered to increase and maintain satisfaction: be aware of parents who lack a good friend and family network; be more attentive to parents with very preterm infants and parents with longer NICU stays; provide support to siblings; and give greater attention to parents' needs for continuity of care, follow-up, and information. Due to the response rate, the geographical spread of the hospitals and the statistical validation of the survey, the generalizability of the study is rather strong in Scandinavian settings.

The NSS-8 could possibly also be used to compare satisfaction between units and countries, and monitor changes over time.

Abbreviations

FCC: Family-Centred Care; GA: Gestation age; NICU: Neonatal Intensive Care Unit; NSS-8: Neonatal Satisfaction Survey 8

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Availability of data and materials

The data used in the current study are available from the corresponding author on reasonable request.

Authors' contributions

IHH, design, data collection, transcription, analysis, interpretation of data; MFS, drafting the manuscript and revising it critically for important intellectual content, writing assistance, and analysis; VCI, drafting the manuscript and revising it critically for important intellectual content; EN, data analysis; RO, drafting the manuscript and revising it critically for important intellectual content. All authors have read and approved the study.

Ethics approval and consent to participate

Permission to conduct the study was obtained from the Regional Committees for Medical and Health Research Ethics in Norway (Ethics Reference Number 2015/386) (REK Nord). Signed informed consent was obtained from each participant before they participated in the study. Participants were informed of their rights to withdraw from the study at any time. The anonymity of participants was maintained, and assurance was given that all information would be treated in absolute confidence. Participants were also provided with a written information sheet on the study and their rights regarding participation and the option of withdrawing at any time.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Appendices 1

Neonatal Satisfaction Survey (NSS-8)

Candidate nr

unit nr

Please tell us about your experiences as a carer for an infant admitted to a neonatal unit?

The aim of this study is to improve services for children and families cared for within neonatal services. We would therefore like to ask you about your experiences as a carer who has stayed in this hospital. We should be very grateful if both mothers and fathers of the children were to complete this questionnaire. It is also important that you do so independently and on your own without asking anyone else, and using your one survey form. Please mark your answer for each question with only one cross, preferably close to the centre of each box provided. The completed forms will be treated as confidential and you will not be personally identified by the answers you give. Please return the questionnaire to the place show to you within this neonatal unit.

IMPORTANT: You should read the information leaflet prepared for and given to those who have been asked to participate in this survey. If you agree to take part, please place a cross in the box below. This is how you give your consent to participate in the survey as described in the information leaflet.

Yes, I wish to take part.

Your Overall Impression

	Very dissatisfied	Quite dissatisfied	Neither satisfied or dissatisfied	Quite satisfied	Very satisfied
1. All in all, how satisfied or dissatisfied are you with the treatment the child/ children received at the hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. All in all, how satisfied or dissatisfied are you with how you as a next of kin were treated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Neonatal Satisfaction Survey (NSS-8)

Candidate nr

unit nr

Care and treatment

	Not at all	In small degree	In some extent	Largely	Very large extent
3. To what extent did you experience that a permanent group of care givers/nurses were looking after you and your child/children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. To what extent did you experience that the employees co-operated on the treatment and care the child/children received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Did you experience that the treatment and care the child/children received at the hospital followed a thought-out plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. To what extent did you experience that you were taken care of upon arrival at the unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. To what extent did you experience that the child/children were taken care of upon arrival at the unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. To what extent did you experience that you were taken care of later in the process?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. To what extent did you experience that the child/children were taken care of later in the process?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. To what extent did you experience that you received guidance / training in meeting your child's/children's needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I experienced that both mother and father were treated equally by the unit.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Neonatal Satisfaction Survey (NSS-8)

Candidate nr

unit nr

Not at all In small extent In some extent Largely Very large extent

12. To what extent did you experience that the care personnel: (place only one cross for each line)

- | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| - Took your family situation into consideration? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Provided relief or assistance to the admitted child/ children during the stay? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Informed about your responsibilities as next of kind to the child/children at the hospital | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Had consideration and care for the child/children? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Had consideration and care for you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Were interested in hearing your opinions as a next of kin? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Gave you explanations in a way you understood? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Were available/stayed in reasonable proximity to the child/children? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Signalled that they had time for you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Appeared professionally competent? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Comments:

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Neonatal Satisfaction Survey (NSS-8)Candidate nr unit nr

- | | Not at all | In small extent | In some extent | Largely | Very large extent |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 13. Were you angry, upset or disappointed in the hospital personnel during the stay? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. I experienced that the personnel showed understanding and respect for our situation. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. While the child/children were admitted, did you experience that the personnel kept agreements regarding ringing you (when you were not at the unit) in the event of changes in the child's/ children's condition or treatment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Comments:

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Doctors

- | | Not at all | In small extent | In some extent | Largely | Very large extent |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 16. To what extent did you experience that one doctor had the principal responsibility for the child/children? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. To what degree do you think the doctors..... | | | | | |
| - Showed care and consideration for the child/ children? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Showed care and consideration for you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Were interested in hearing your opinions as next of kin? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Gave you explanations in a way you understood? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Gave you and your child/children sufficient information regarding the prognosis/outcome? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Appeared professionally competent? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Took your family situation into consideration? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Signalled that they had time for you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Comments:

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Neonatal Satisfaction Survey (NSS-8)

Candidate nr

unit nr

Visit

	Not at all	In small extent	In some extent	Largely	Very large extent
18. All in all, how satisfied were you with the conditions for visiting at the unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. All in all, how satisfied were you with the routines for visiting at the unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. All in all, how satisfied were you with the conditions for visiting your child/children/	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. All in all, how satisfied were you with other child`s/children`s/ next of kins` visits?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Facilities

	Very poor	Pretty bad	Both/and	Pretty good	Very good	Not applicable
22. What do you think about the following conditions at the department?						
Bath/shower/toilet facilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quietness in the patients room.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offer of food/rest, lodging, pump room, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient/guardian proximity (confidentiality, privacy, possibilities for changing cloths, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Neonatal Satisfaction Survey (NSS-8)

Candidate nr

unit nr

Siblings

	Not at all	In small extent	In some extent	Largely	Very large extent	Not applicable
23. To what extent were the siblings' reactions paid attention to? (taking care of siblings, practical assistance, place for siblings to be)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. To what extent are you satisfied with the activities offered to the child's siblings? (TV, games, books, toys, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Information

	Not at all	In small extent	In some extent	Largely	Very large extent
25. Do you think you were given the necessary information about why tests and examinations were carried out while the child/children were admitted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Do you think you were given the necessary information about how tests and examinations were to be carried out while the child/children were admitted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. During the child's/children's admission, do you think you were given the necessary information about the effects and side effects of new medication given to the child/children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Did you experience that the information you received was adequate and given in an understandable way during the stay at the hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Neonatal Satisfaction Survey (NSS-8)

Candidate nr

unit nr

Parents anxiety

	Not at all	In small extent	In some extent	Largely	Very large extent
29. To what extent did you experience stress/anxiety/sleeplessness in connection with the stay at the unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. During the period of the child's/ children's admission, were you at any time afraid that the child/children would not survive?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. While the child/children were admitted, were you at any time afraid that the child/children would have delayed injury/after-effects?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Discharge

	Not at all	In small extent	In some extent	Largely	Very large extent
32. Do you think you were given the necessary information for the period following discharge?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. To what extent do you feel confident with managing the necessary follow-up care of the child/children after home-coming? (i.e. breast feeding/nutrition, administering medication, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Have you been given information about what to do if the child/children become ill/have a relapse/need medical attention after returning home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Neonatal Satisfaction Survey (NSS-8)

Candidate nr

unit nr

Questions about your child

35. In which gestation was your child/ children born?

	24–28 week	29–33 week	34–37 week	38–42 week	Over 42
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

36. How many children did you get?

	Simple birth	Twins	Triplets	Multiple births
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

37. Why was the child/children hospitalized? (Inpatient diagnosis/suspected) (you may tick several routes. Tick off the current route with such TV1/TV2).

	Syndrom	Infection	Glucose problem	Breath problem	Spasm
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Food/weight problem	Photo-therapy	Abstinence	Hearth failure	Observation
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Describe about other things:

.....

.....

38. Duration of stay

	Under 1 week	1–2 week	Over 4 week	Over 4 week
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. Have your child / children previously been hospitalized in the department?

	Under 1 week	1–2 week	Over 4 week	Over 4 week
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

40. How would you characterize your child/children's health now?

	Exelent	Very good	Good	Quite good	Poor
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

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Neonatal Satisfaction Survey (NSS-8)Candidate nr unit nr **Questions about you as a parent**

41. Were you alone as dependents with child/children at the hospital?
 Yes, I was alone Yes, I was alone part of the time No, it was several dependents
42. Did you get the support you needed among friends/family during your stay?
 Not at all In small extent In some extent Largely Very large extent
43. Did you get practical help from friends or family to fit other children while the child/children were hospitalized?
 Yes No Wanted/needed not such assistance Have no other children
44. How long driving distance do you have from home to hospital?
 0–0.5 hours 0.5–1 hours 1–2 hours Over 2 hours
45. Who has answer the survey?
 Mother Father Other
46. What is your age? Number of years:
47. What is your native language?
 Norwegian Sami Other Nordic native Other European native Not European native
48. What is your highest completed education?
 Primary school High school College or university 4 years or less College or university more than 4 years
49. What was your main income before the child/children were born?
 Employed In education Home working Maternity leave/sick/insured Others
50. Sivilian
 Married Cohabiting Separated Single

Referanser:

Hagen, Inger Hilde; Svindseth, Marit Følsvik; Nesset, Erik; Orner, Roderick; Iversen, Valentina Cabral. (2018) Validation of the Neonatal Satisfaction Survey (NSS-8) in six Norwegian neonatal intensive care units: a quantitative cross-sectional study. BMC Health Services Research.

Appendices 2

Edit to Publish AS

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Certification of translation

We at Edit to Publish AS hereby confirm the certification of the translated document entitled “Neonatal satisfaction survey”, for Inger Hilde. The document has been translated from Norwegian into English by S. Anne Colling, a translator authorized by the Norwegian Ministry of Education and Research on 14 December, 1999. Thereafter, the document was retranslated by Hege Lepri and then quality controlled by a proof reader.

Any questions about the translation or certification can be directed to the following e-mail address: richard@e2publish.com. Questions can also be addressed by calling +47 41 47 21 60.

Sincerely,

A handwritten signature in black ink, appearing to read 'Richard Whitehead', is written over a light blue horizontal line.

08 September 2015
Dr. Richard Whitehead
E2Publish, by Edit to Publish AS