



Parents' presence and participation in medical rounds in 11 European neonatal units

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ABSTRACT

Background: Parents' involvement during hospital care is beneficial for preterm infants and their parents. Although parents are encouraged to be present in many neonatal intensive care units (NICUs), little is known about their role during medical rounds.

Aims: To study parents' presence in the NICU, the degree of parents' participation during medical rounds, and to identify underlying factors for participation.

Study design and subjects: A prospective study was performed in 11 neonatal units in six European countries including parents of preterm infants born before 35 gestational weeks.

Outcome measures: Parents' presence and the degree of participation (7-point Likert scale) during medical rounds were asked using a text-message question sent to the mobile phone of each parent separately.

Results: A total of 241 families were included in the study; mothers responded to 630 and fathers to 474 text-message questions, respectively. In studied units, mothers were present during medical rounds on 62.5% to 91% and fathers 30.8% to 77.8% of the days. The degree of mothers' and fathers' participation also varied between units ($p < 0.001$ and $p = 0.022$, respectively). In multivariate analysis, parents' presence increased by increasing gestational age ($p = 0.010$), fathers' education ($p = 0.009$), and by the policy in the unit to invite parents to medical rounds ($p = 0.036$). The background characteristics did not explain the degree of participation.

Conclusion: There is significant variation between neonatal units in how they include parents in medical rounds. Only few background characteristics explained the differences suggesting that unit culture plays a major role in welcoming parents to participate.

1. Introduction

Patient- and family-centred care (FCC) are still developing concepts in paediatrics and neonatology [1,2]. Encouraging parental presence and parent-infant closeness, listening to parents' observations and opinions, and aiming to share responsibility and decision making about the care of the infant are important elements of this concept [1–4]. Earlier, the role of parents has been more passive, mainly serving as only recipients of information. Although it is common today to invite parents to be present in the neonatal intensive care unit (NICU), steps should be taken to involve parents in a shared-decision making process during medical rounds [5].

Care cultures encouraging parent-preterm infant closeness have

been shown to improve later development of preterm infants. Preterm infants who are treated in single-family rooms have been shown to have better weight gain, fewer painful procedures, decreased infection rate, and improved cognitive and language development [6,7]; skin-to-skin contact has been shown to reduce, for example, mortality, risk of neonatal sepsis, and hospital readmissions [8,9], in addition to predicting better cognitive and neuropsychological development up to 10 years of age [10]. Furthermore, mothers providing calming sensory experiences to their preterm infants early during NICU stay have been found to improve infant short- and long-term brain development and behavioral outcomes [11,12]. Even more, higher maternal involvement during NICU stay has been associated with better language and cognitive scores at 18 months [13]. Therefore, many positive developmental

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Table 1a
Infant and family characteristics for 11 neonatal units.

	Finland		Sweden		Estonia		Italy	Spain	Norway		
	Turku	Uppsala	Danderyd	Huddinge	Tallinn	Tartu	Como	Madrid	Drammen	Bergen	Tromso
N	30	28	26	19	21	14	18	27	27	27	11
Infant/family characteristics											
Gestational age (weeks), mean	31 ^{3/7}	28 ^{0/7}	33 ^{1/7}	32 ^{2/7}	32 ^{4/7}	32 ^{4/7}	31 ^{0/7}	30 ^{4/7}	32 ^{4/7}	30 ^{6/7}	31 ^{5/7}
Time to first message (days), mean	7.0	6.9	8.4	7.1	7.2	5.9	6.2	7.1	7.1	7.4	9.2
Time to hospital (min), %											
< 30	60.7	50.0	82.6	50.0	73.7	69.2	76.5	92.6	59.3	63.0	60.0
30–60	7.1	0	13.0	33.3	0	0	23.5	7.4	33.3	11.1	0
> 60	32.2	50.0	4.4	16.7	26.3	30.8	0	0	7.4	25.9	40.0
Home living sibling, yes %	59.3	53.6	33.3	31.2	31.6	61.5	27.8	29.6	59.3	55.6	45.5
Maternal education, higher %	8.0	60.0	73.9	50.0	63.2	38.5	41.2	37.0	77.8	25.9	62.5
Paternal education, higher %	12.0	52.0	65.2	21.4	41.2	15.4	11.8	29.2	65.4	37.0	25.0
Maternal employment, paid work %	59.3	88.5	73.9	78.6	63.2	76.9	83.3	77.8	92.6	88.9	90.0
Paternal employment, paid work %	88.5	84.6	87.0	92.9	94.7	92.3	83.3	84.0	96.2	96.3	88.9
Maternal age (year), mean	31.0	32.1	32.9	30.9	30.5	29.2	35.9	34.8	33.2	31.6	31.5
Paternal age (year), mean	32.6	32.9	34.0	32.5	33.6	33.7	39.5	35.8	34.3	33.2	34.9
Foreign language, %											
No	85.2	85.7	75.0	62.5	100.0	100.0	100.0	92.6	74.1	81.5	100.0
One parent	3.7	7.1	20.8	18.8	0	0	0	7.4	14.8	11.1	0
Both parents	11.1	7.1	4.2	18.8	0	0	0	0	11.1	7.4	0

outcomes seem to have resulted from efforts to increase parent-infant closeness occurring in many NICUs already. Allowing parents to be involved during medical rounds would add a new layer to these FCC efforts.

Many units have, indeed, started to encourage and expect parents' participation in medical rounds [5,14]. However, there are differences in these policies and practices between countries and units [5,14–17]. Many units still do not allow parents to be present during medical rounds [15,16]. The obstacles to achieving increased parental presence can include unit policy about parents' visiting, concerns about confidentiality and teaching of trainees, and concerns regarding high levels of noise and light [15,17,18]. Studies report that parents want to attend medical rounds [17,19], but their willingness to participate in decision-making varies according to the nature of the decision being made and the condition of the child [5,20]. Medical rounds are a natural setting to exchange information between parents and the healthcare team, and thereby can be an essential element in establishing parent-staff partnerships [21,22]. Family-centred medical rounds require new, mutualistic communication skills and open information sharing. These skills may not have been learned by the health care team [2,23,24], nor the doctors in training, who would gain important communication skills included in the goals of specialist training [21,22].

The existing studies regarding parental presence during medical rounds are small surveys describing practices on the unit policy level rather than actual parent participation. Studies on shared decision-making primarily focus on withdrawing care or have been carried out in paediatric intensive care setting [14,19,25–31]. To our knowledge, there are no studies assessing parents' own perspectives on their role in the decision-making process during neonatal intensive care.

The objective of this study was to evaluate parents' presence and the degree of their participation in discussions during medical rounds in 11 European NICUs. We hypothesized that there is variation in how different units include parents in medical rounds. In addition, we wanted to identify family and hospital characteristics that may facilitate or hinder parents' integration in medical rounds.

2. Methods

The International Closeness Survey was conducted as a part of research carried out by the Separation and Closeness Experiences in Neonatal Environment (SCENE) Study Group. SCENE is a multi-disciplinary group of international professionals who are undertaking

research to identify, construct, implement, and evaluate best practices in supporting physical and emotional parent-infant closeness during neonatal care (<https://www.utu.fi/scene>).

2.1. Design

This multi-centred prospective survey was conducted from September 2013 to August 2014 in 11 NICUs in six European countries. The participating units were levels II–III c, as defined by the American Academy of Paediatrics [22], from Finland (Turku), Sweden (Danderyd, Huddinge and Uppsala), Norway (Bergen, Drammen and Tromso), Estonia (Tallinn and Tartu), Spain (Madrid) and Italy (Como).

2.2. Study population

The study population was parents of preterm infants born before 35 weeks of gestation. The exclusion criteria were 1) triplets or higher order multiples, 2) no common language, 3) parent not having a mobile phone, or 4) the infant was likely to die. The sample size was set at 30 families for every participating NICU. From 528 eligible families, 440 were approached at the infants' postnatal age of 2 to 6 days. Because of missing data or parents' refusal in 172 cases, a total of 262 families participated (mother and father, 208; only mother, 48; only father, 6) [32]. Questions about medical rounds were answered by 241 families.

2.3. Data collection methods

Every evening during the infants' hospital stay, in a random order 1 out of 9 text-message questions was sent to both parents via mobile phone. The questions covered different aspects of FCC: active listening, parental participation, individualised guidance, shared decision-making, mutual trust, individualised information, and emotional support (Supplement 1). The results regarding parents' satisfaction with FCC in the neonatal unit according to 8 different text-message questions are reported by Raikila et al. [32]. Information about parents' presence and participation in medical rounds has not been reported before. This was measured using text-message question number 7: "To what extent did you participate in discussions during the doctor's round/visit?". The responses were rated on a 7-point Likert scale (1–7, with higher values being more positive). Parents responded "0" if they were not in the unit on that day. We report parental presence only for the days that parents

Table 1b
Hospital characteristics for 11 neonatal units.

	Finland		Sweden		Estonia		Italy	Spain	Norway		
	Turku	Uppsala	Danderyd	Huddinge	Tallinn	Tartu	Como	Madrid	Drammen	Bergen	Tromsø
N	30	28	26	19	21	14	18	27	27	27	11
Hospital characteristics											
More than 500 admissions per year	Yes	No	Yes	Yes	No (MH) No (PICU) Yes (SD)	No (MH) No (PICU) No (SD)	No	Yes	No	No	No
Time to first SSC < 10 h, %	16.0	52.0	82.6	75.0	40.0	66.7	29.4	11.1	81.5	48.2	88.9
Opportunity to stay overnight	No	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No
Parents invited to rounds	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes

MH – maternity hospital; PICU – paediatric intensive care unit; SD – step down, level II neonatal unit; SSC – skin-to-skin contact.

responded to the text message question about medical rounds, which may not cover all hospital care days.

Parent and infant characteristics (presented in Table 1a) were collected from parents through a questionnaire at discharge, and unit characteristics (Table 1b) were collected through a questionnaire sent to each unit's contact person. Parents' education was classified in three categories (obligatory school; more than obligatory school but less than university; university degree). University of applied sciences degrees were considered equal to university degrees in all countries except Finland. Foreign languages were considered to be all languages that were not native languages, except in Estonia, where Estonian and Russian were both considered as native languages, and in Finland, where Finnish and Swedish were native languages.

Hospital characteristics measured include unit size, opportunity for parents to stay overnight in the unit, and whether parents were invited to medical rounds. In Estonia, preterm infants are treated in three separate units. Preterm infants from this country are referred from maternity hospitals to children's hospitals' paediatric intensive care units or step-down units depending on the need for invasive respiratory support, perioperative care and/or a longer hospital care.

2.4. Ethics

The study protocol was approved by the boards of ethics of all participating hospitals or countries.

2.5. Statistical analysis

Descriptive statistics were used to characterize the infants and families in the study hospitals. The mothers' and fathers' mean scores for participation were calculated as arithmetic means of all answers on a 7-point Likert scale (excluding zero-responses). Parents' non-presence at units (zero-responses proportions) and participation scores by unit were compared using Chi-square and Kruskal-Wallis test respectively. Associations between participation scores, proportion of zeros from all responses, and parents' total scores for the quality of FCC (excluding the question about participation) were studied using the Spearman correlation coefficient.

The association between participation scores and the number of times the question was responded to was assessed by means of mixed generalized linear models with a responding parent as a random factor. The impact of parent's presence and parent's participation on family/hospital characteristics (gestational age, time to first message, time to hospital from home, home living siblings, parents' education and employment, parents' age, foreign language, units' admissions, first skin-to-skin contact, opportunity to stay overnight, inviting to rounds; all presented in the Tables 1a and 1b) was assessed using uni- and multivariate mixed generalized linear models with hospital as a random factor. For multivariate modeling, independent variables were chosen based on previous knowledge about the topic (without considering the

results of univariate models). In the case several units were included in one centre, such as with Tallinn and Tartu, Estonia, the characteristics at the unit with the biggest number of admissions was used in the model. These were the step-down units in both study centres in Estonia.

Missing values were not imputed. SAS software was utilized for statistical analysis.

3. Results

3.1. Background of the study population

A total of 241 families of preterm infants (211 mothers and 144 fathers) were included in the study about parents' participation in medical rounds in 11 neonatal units. The mean gestational age of infants varied from 28^{0/7} to 33^{1/7} weeks between the neonatal units.

Mothers and fathers responded to 630 and 474 text-message questions about medical rounds, respectively. Parental response to text-message questions varied from 1 to 10 responses. Mothers responded an average of 2.4 times and the fathers responded an average of 2.0 times. Of the answers, 303 indicated that the parent had not been in the unit (zero answer) on that day. Mothers and fathers sent 511 and 290 text-messages indicating the degree of parent's participation in discussions during medical rounds, respectively.

The study populations of each neonatal unit are described in Tables 1a and 1b. Families lived mostly within a 30-minute drive from the hospital in all sites. On average, mothers were 29.2 to 35.9 years old and fathers 32.5 to 39.5 years old. There were siblings in 27.8% to 61.5% of the families. The majority of our study population spoke the native language of the country.

Five of the neonatal units had > 500 admissions per year. There were significant differences in unit practices related to parental involvement. In six hospitals, most infants had their first skin-to-skin contact within 10 h of birth. Five of these hospitals and one other hospital included in this study offered parents an opportunity to stay overnight in the neonatal unit. Eight neonatal units had a practice of regularly inviting parents to participate in the medical rounds.

3.2. Parents' presence during medical rounds

In all units, mothers were present during medical rounds most of the days. The proportion of days that mothers were present varied between the units from 62.5% to 91%, $p = 0.002$. In eight out of the 11 units, fathers were present during medical rounds most of the days. The proportion of days that fathers were present varied between 30.8% and 77.8%, $p < 0.001$. The data for all units is presented in Table 2.

3.3. The degree of parent's participation during medical rounds

There was no association between the degree of parent's participation and the number of responses (mothers, $p = 0.479$ and fathers,

Table 2

The number of parents' responses to the text-message questions about participation in the discussions during the medical rounds; the parents' presence in the unit and parents' total satisfaction to family-centred care (FCC) measured by eight questions.

	Finland		Sweden		Estonia		Italy	Spain	Norway		p-Value	Overall Mean
	Turku	Uppsala	Danderyd	Huddinge	Tallinn	Tartu	Como	Madrid	Drammen	Bergen		
N	30	28	26	19	21	14	18	27	27	27	11	
Mothers' responses, n	79	109	33	27	44	32	67	79	54	75	31	
Fathers' responses, n	64	77	35	18	23	13	64	42	46	66	26	
Mother in the unit (% of days)	77.2	89.0	84.8	74.1	84.1	62.5	91.0	72.2	88.9	81.3	67.7	0.002
Father in the unit (% of days)	56.2	72.7	77.1	77.8	60.9	30.8	71.9	61.9	45.7	53.0	42.3	< 0.001
Mothers' mean satisfaction of FCC	6.1	5.8	6.2	6.1	5.6	5.4	4.7	5.7	6.4	5.8	5.7	< 0.001
Fathers' mean satisfaction of FCC	6.1	6.1	5.8	6.1	5.4	5.5	4.4	5.2	6.1	5.7	5.9	< 0.001

p = 0.571). Mothers gave more positive responses (overall mean 4.60, SD 1.98) than fathers (overall mean 4.51, SD 1.95) but this difference was not statistically significant, p = 0.083. Mean score varied from 2.21 to 6.12 between the neonatal units on a 7-point Likert scale for mothers and between 3.29 and 5.78 for fathers. In six units, mothers gave higher mean scores than fathers.

The ratings parents gave about the degree of their participation during medical rounds varied significantly between the 11 neonatal units (for mothers p < 0.001; for fathers p = 0.022). There were differences between and within countries (Fig. 1). Parents in Uppsala, Sweden rated their participation in discussions during medical rounds the highest.

3.4. Associations between the background characteristics and parents' presence

In multivariate models, parents' presence associated statistically significantly with gestational age, fathers' education and unit's policy about inviting parents to medical rounds (Table 3). The more mature the infant was at birth, the more likely the mother was present during the medical rounds (p = 0.010). Fathers who had higher education were more likely to be present in the unit during the medical rounds (p = 0.009). When the unit's policy was to routinely invite parents to medical rounds, the mothers were more likely to be present (p = 0.036).

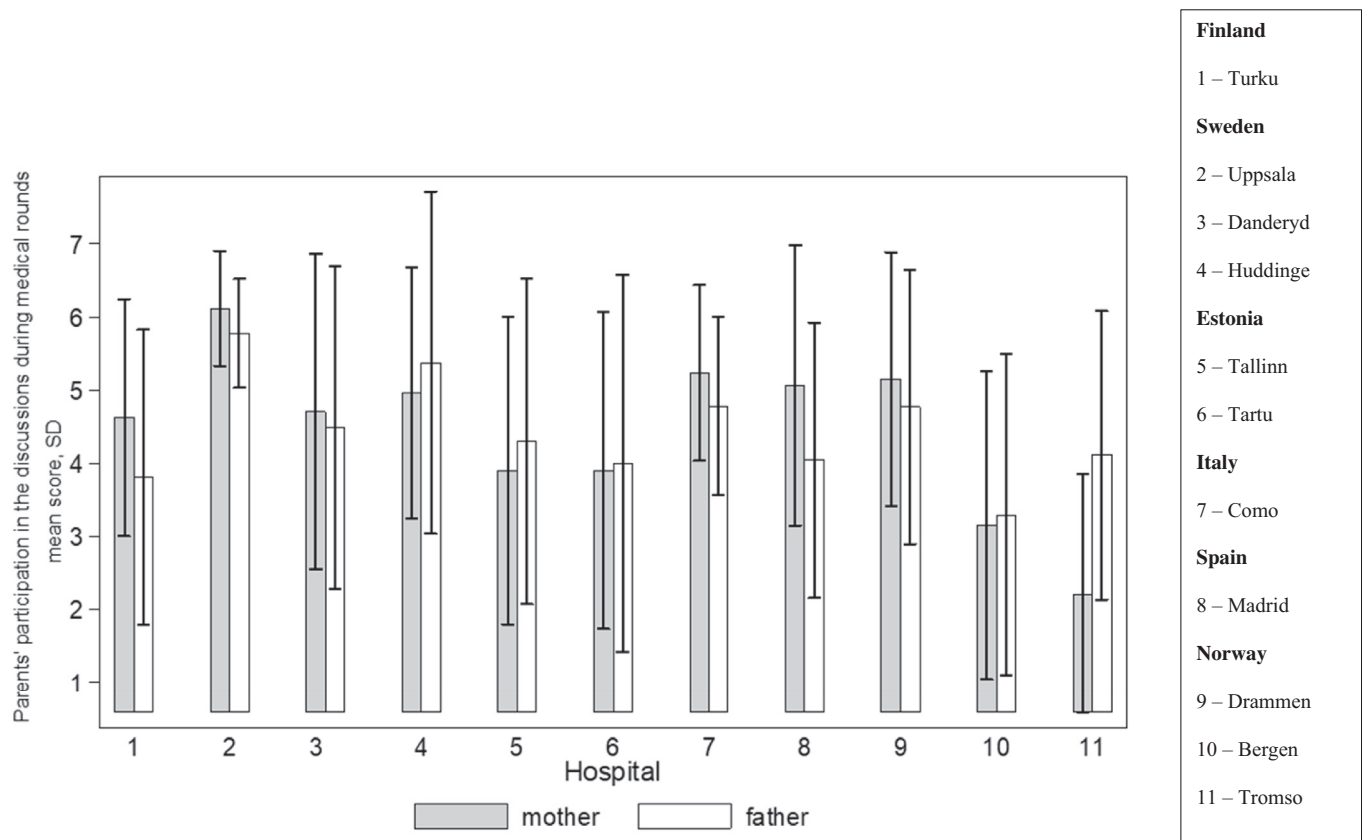


Fig. 1. Parents' degree of participation in the discussions during medical rounds in 11 neonatal units.

Table 3
Association between background characteristics and parents' presence in the unit.

	Mother's presence in the unit				UV coef	Father's presence in the unit		
	UV coef	UV p-value	MV coef	MV p-value		UV p-value	MV coef	MV p-value
Infant/family characteristics								
Gestational age (week)	−0.035	0.001	−0.168	0.010	−0.035	0.001	−0.012	0.250
Time to first message (hour)	0.007	0.498	0.075	0.165	0.000	0.976	0.072	0.220
Time to hospital (< 30/30–60/ > 60 min)	0.022	0.565	−0.105	0.632	0.055	0.219	0.058	0.807
Home living sibling								
No	0.000				0.000			
Yes	0.066	0.291	0.321	0.340	0.018	0.805	0.152	0.663
Maternal education								
No higher	0.000				0.000			
Higher	−0.167	0.014	−0.632	0.132	−0.015	0.842	0.491	0.284
Paternal education								
No higher	0.000				0.000			
Higher	−0.071	0.317	0.270	0.501	−0.192	0.013	−1.125	0.009
Maternal employment								
Paid work	0.000				0.000			
No paid work	−0.020	0.794	0.238	0.591	−0.017	0.847	−0.121	0.796
Paternal employment								
Paid work	0.000				0.000			
No paid work	−0.108	0.312	−0.141	0.811	0.036	0.765	0.271	0.658
Maternal age (year)	0.003	0.577	0.020	0.541	0.003	0.639	0.049	0.172
Foreign language (no/one parent/both parents)	0.048	0.456	0.359	0.265	0.062	0.381	0.432	0.259
Hospital characteristics								
More than 500 admissions/year								
No	0.000				0.000			
Yes	−0.006	0.953	0.172	0.637	−0.222	0.017	−0.918	0.107
Time to first SSC								
Less than 10 h	0.000				0.000			
More than 10 h	0.073	0.300	−0.313	0.427	0.194	0.011	0.305	0.459
Opportunity to stay overnight								
No	0.000				0.000			
Yes	−0.200	0.009	−0.506	0.219	−0.132	0.206	−0.031	0.955
Invited to rounds								
No	0.000				0.000			
Yes	−0.214	0.019	−1.060	0.036	0.119	0.329	−0.098	0.873

UV – univariate model; MV – multivariate model; SSC – skin-to-skin contact.

3.5. Associations between the background characteristics and the degree of parents' participation

In univariate analysis, the opportunity for parents to stay overnight in the neonatal unit only associated statistically significantly with the degree of participation for the fathers' ($p = 0.012$). In the multivariate analysis, none of the background characteristics associated statistically significantly with the degree of parents' participation (results not shown).

3.6. The quality of FCC and the parents' degree of participation during medical rounds

Parents' rating about the overall quality of FCC of the neonatal unit varied between 4.7 and 6.4 on a 7-point Likert scale for mothers and 4.4 to 6.1 for fathers (Table 2). Mothers' and fathers' ratings of the overall quality of FCC correlated with the degree of their participation in discussions during medical rounds ($p < 0.001$ for both) (Fig. 2a and b). A high rating of the overall quality of family-centred care seemed to be a prerequisite for high scores for participation during medical rounds.

4. Discussion

This multi-centre international study showed that parents' presence and the degree of their participation during medical rounds varied significantly between the units in Europe. The factors increasing parental presence during medical rounds included unit policy regarding inviting parents to medical rounds, higher gestational age of the infant, and higher education of the father. High degree of participation during

medical rounds was associated with a high level of other FCC attributes, but with none of the infant, family or unit background characteristics studied.

To our knowledge, this is the first study prospectively assessing parents' presence and the degree of their participation in medical rounds in the NICU. Our study provides prospective data about parents' participation from their own perspective. Previous studies have reported variation in parents' access to medical rounds on policy level. In a European study, medical rounds were the most common limitation to parental presence, as 45% (79/175) of the units did not allow parents to be present during medical rounds [15]. Among 153 units in the United Kingdom, the unit managers reported that 86% of the units allowed parents to be present in medical rounds [16]. It might be that parental participation is overreported when policies are reported compared to the actual participation asked from the parents. In our study, 8 out of 11 units actively invited parents to participate in medical rounds. However, parents' daily presence during medical rounds in those units varied from 68% to 89% among mothers and from 42% to 78% among fathers.

Our study suggests that parents' participation in discussions during medical rounds is the most challenging part of FCC, as parents gave high ratings to other aspects of FCC if they gave high ratings to their participation during medical rounds. Medical rounds might be the last practice in the daily routines of neonatal intensive care in which parents will be integrated. Parents' participation may be hindered by a feeling of incompetency if medical rounds have a professional-centred approach, medical terminology dominates, and/or active listening is missing [5].

Only few infant and family characteristics explained parental

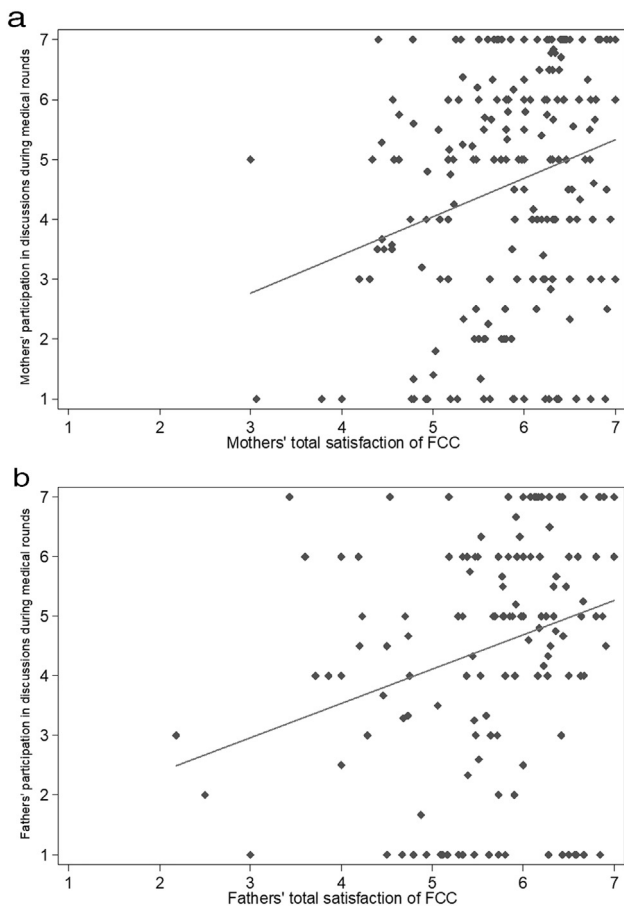


Fig. 2. a. Correlation between the mothers' total satisfaction of family-centred care (FCC) measured by eight questions and mothers' participation in the discussions during medical rounds ($\rho = 0.245$, $p < 0.001$). b. Correlation between the fathers' total satisfaction of family-centred care (FCC) measured by eight questions and fathers' participation in the discussions during medical rounds ($\rho = 0.315$, $p < 0.001$).

presence during the medical rounds. The only significant infant characteristic was higher gestational age, which associated with increased parental presence during medical rounds. A cross-sectional study about the preferences of 132 parents showed that decision-making is influenced by urgency, medical expertise needed, and familiarity [20]. Parents prefer to take part in decision-making for decisions that may be potentially harmful or at high risk for the infant and those that are familiar. They prefer to leave urgent matters requiring medical expertise to the medical team [20]. Additionally, an observational study showed that parents preferred to leave the decision-making to healthcare professionals in emergency situations and if the infant's condition was critical [5]. As preterm infants with higher gestational age are more often in stable condition, we speculate that parents might feel more confident and familiar in the shared-decision making process under these circumstances. The only significant family characteristic was father's education, which associated with increased presence during medical rounds. Fathers with higher education might have more knowledge about health issues, and therefore they may want to be present during decision-making about the care of their child.

As only few infant and family characteristics explained parents' presence during medical rounds, barriers and facilitators to parents' presence and participation are likely to be on the unit level. Barriers and facilitators influencing parents' presence and their active participation may be affected by unit policies, as well as the work load and number of healthcare professionals working with each family during the day. In our study, the unit's policy to regularly invite parents to

medical rounds influenced parents' presence during medical rounds, but not the degree of their participation. Previous studies highlight the importance of collaboration between parents and staff, as well as special training for healthcare professionals on relational communication [33–36]. When the medical staff is appropriately trained and values the collaboration with parents, there will be more positive attitudes among the parents and the medical team [34]. It has been shown that neonatologists play an important role in integrating families in discussions during medical rounds [5]. Parents' presence and participation during medical rounds are supported by a welcoming atmosphere in the unit and good teamwork within the healthcare team [5,14]. Supporting systematic change in care culture is an essential part of building a family-centred neonatal care environment, and thus supporting parent-infant closeness. It is shown that parents feel close with their infant when they can be part of the decision-making process [37].

Social benefits of the unit's country may facilitate fathers' presence. However, this study showed that the differences in the fathers' presence were not explained by social benefits of the country, as there were also differences within countries. It seems that paternal leave and other social benefits are necessary, but not sufficient facilitators for fathers' presence. Therefore, care culture in the unit seems to be a key facilitator for fathers' presence and participation. Future studies are needed to further analyze the association between parents' participation, healthcare professionals' work load, and state support for paternal leave in every country.

This study has limitations as well as strengths. Even if the technology worked smoothly in most countries, there were some technical difficulties in delivering text-messages in Estonia and Norway, which resulted in missing data from these countries. Our study design did not allow us to analyze the data on the individual patient level so we cannot provide disease-related or medical condition related data.

In future studies, it would be important to study the impact of parental participation on health outcomes of the infant, as well as on well-being and satisfaction of the parents and medical staff. It would be interesting to study whether parents' active role during medical round decreases medical errors.

5. Conclusion

This study showed that there is a significant variation between European neonatal units in how they include parents in medical rounds. Only few infant or family characteristics explained the differences, suggesting that unit culture plays a major role in welcoming the parents to participate. This was further supported by within-country variation suggesting that social benefits, even if important, are not sufficient to support parents' participation without support from the individual hospital's care culture. Therefore, it is important to create and support a partnership between the families and health-care team in the NICU. This study identified units which have been successful in this endeavour.

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Conflict of interest statement

Authors declare no conflicts of interest.

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