

Unscheduled conversations with parents in Neonatal Intensive Care

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ABSTRACT

Title: Unscheduled conversations with parents in neonatal intensive care

Background: Parents often speak to nurses at their infant's bedside and have indicated that these conversations can be very important. During these unscheduled conversations, nurses make parents feel confident in their parental role and increase their activation and involvement in caring for their infant. Strengthening the parent-infant bonding contributes to physical, psychological and emotional development of their infant.

Aim: From a parent's perspective identifying nature, content, value, and impact of unscheduled conversations among parents and nurses and how these conversations inform planning infant care and involvement in caring for the infant in order to empower parents.

Method: A descriptive qualitative study using semi-structured web-based interviews was conducted among parents who had a premature infant admitted to the NICU. Thematic analysis was performed.

Results: Twelve parents of fourteen infants between 26-39 gestational age were included. Parents searched for trust in issues they heard when they were bedside at their infant. Once they gained this feeling of trust, they talked about their personal life, well-being and thoughts. Parents heard how to provide basic care which strengthened them in being in control over their infant; they got empowered in their parental role.

Conclusion: Parents established a relationship with nurses as they searched for trust during unscheduled conversations. Words of encouragement and support provided parents the opportunity to collaborate in providing infant care and make decisions regarding their infant. Parents became independent and in control over their infant.

Recommendations: Implication for practice contains the importance of nurses creating parental awareness regarding self-care during admission to remain powerful in providing care for their infant. Furthermore, nurses should become aware regarding value and importance of unscheduled conversations. Further research is needed to determine the strategies of creating this awareness.

Keywords: NICU, parents, unscheduled, conversations, bedside

SAMENVATTING

Titel: Ongeplande gesprekken met ouders op de Neonatologie intensive care

Achtergrond: Ouders spreken vaak met verpleegkundigen aan bed van hun kind op de NICU. Ouders geven aan dat dit belangrijke gesprekken zijn. Tijdens deze gesprekken zorgen verpleegkundigen ervoor dat ouders zich zeker voelen in hun ouderrol en vergroten zij hun betrokkenheid in het zorgen voor hun kind. Het versterken van de hechting tussen ouder en kind draagt bij aan de fysieke, psychische en emotionele ontwikkeling van het kind.

Doel: Identificeren van inhoud, waarde en impact van ongeplande gesprekken tussen ouders en verpleegkundigen vanuit ouderlijk perspectief. Exploreren hoe deze gesprekken bijdragen aan de wijze waarop ouders de zorg voor hun kind vormgeven en betrokken zijn in de zorg voor hun kind, om in hun kracht te worden gesteld als ouder.

Methode: Beschrijvend kwalitatief onderzoek met online semigestructureerde interviews onder ouders van premature kinderen op de NICU. Thematische analyse werd verricht.

Resultaten: Twaalf ouders van veertien kinderen tussen 26-39 weken zwangerschap werden geïnccludeerd. Ouders zochten naar vertrouwen tijdens ongeplande gesprekken met verpleegkundigen. Eenmaal vertrouwd praatte ouders over hun persoonlijke leven, welzijn en gedachten. Ouders hoorden hoe de basiszorg moest worden uitgevoerd wat hen in hun kracht stelde in hun ouderlijke rol.

Conclusie: Ouders creëerden een relatie met verpleegkundigen door vertrouwen te zoeken tijdens ongeplande gesprekken. Woorden van aanmoediging en steun boden ouders de mogelijkheid om samen te werken tijdens verzorging van hun kind en beslissingen te nemen. Ouders werden onafhankelijk en namen de regie over hun kind.

Aanbevelingen: Verpleegkundigen moeten ouders bewust maken van het belang van zelfzorg om krachtig te blijven in het zorgen voor hun kind. Ook moeten verpleegkundigen zich bewust worden van het belang van ongeplande gesprekken. Toekomstig onderzoek is nodig zodat strategieën ten behoeve van deze bewustwording kunnen worden vastgesteld.

Trefwoorden: NICU, ouders, ongepland, gesprekken, aan bed

INTRODUCTION AND AIM

Each year, nearly 15 million infants are born prematurely (before 37 completed weeks of gestation), equaling to more than 1 infant per 10 births globally¹. Infants born prematurely often require special or intensive care and face greater risks of serious health problems². About 5% of these premature infants are admitted to Neonatal Intensive Care Units (NICU)³, where they experience frequent changes in their condition and therefore their treatment plan. Difficult topics and ethical dilemmas about the infant's current medical condition and prognosis are commonplace and need to be discussed and decided together with the parents⁴⁻⁶. Communication between physicians, healthcare professionals and parents is crucial. It is an essential part of parental support, reducing parents' emotional stress and enhancing parental wellbeing⁷⁻⁹. Parents need open, honest, timely and understandable information, as they are required to place their trust in the hands of the experts^{8,10}. Furthermore, parents need to have their questions answered truthfully when their infant is cared for at the NICU¹⁰. Communication also assists in guiding parents, so they can actively participate in caring for their infant and become closely involved in the decision-making process¹¹. Parents cope by seeking information and finding out what is happening to their infant¹⁰.

Important opportunities for communication are both scheduled and unscheduled conversations. Scheduled conversations, such as family meetings between physicians and parents¹²⁻¹³, often take place in a separate room away from the infant's bedside. The main goal of these conversations is creating a shared dialogue between physicians and parents¹³. Physicians discuss medical conditions, treatment limitations and describe the repercussions of any decisions made¹². Yet, parents often comment about them not receiving the information they want nor understand during these scheduled conversations¹². Physician time constraints and the rapid evolution of clinical events can sometimes prohibit organizing a family conference¹².

However, communication does not only occur at scheduled moments in time, but at any point during admission at the NICU. Unscheduled conversations are those that often take place at the bedside of the infant, initiated by nurses or parents, with the aim of providing parents emotional and practical support. Unpublished data and practice show that these conversations encourage parents to talk and share their needs or concerns and to process information. It also creates the opportunity to bond with parents in a different way than talking about medical issues¹⁴. Unpublished data shows that parents have many of these unscheduled conversations at the infant's bedside, when nurses are conducting their rounds or undertaking their routine clinical role. Nurses guide parents through issues, questions and dilemmas. They also

motivate parents and increase their activation, enablement, involvement and participation in caring for their infant, which is also referred to as ‘parental empowerment’¹⁵. These conversations help parents to feel less lonely in their situation and enables them to cope with the circumstances. It can also make parents feel more confident in their parental role and strengthens the parent’s identity as a parent⁷. By helping parents interact with their infant, the parent-infant bonding is strengthened¹⁶. This parent-infant bonding contributes to physical, psychological and emotional development of their premature infant¹⁷.

Parents have indicated that these unscheduled conversations with nurses can be even more important than scheduled conversations. To the best of our knowledge, no research has investigated the impact of these unscheduled conversations. Knowing the content of unscheduled conversations, allows nurses to have a better understanding and appreciation of these daily conversations. By analyzing data of unscheduled conversations, recommendations can be developed to optimise these conversations. Infant and parental outcomes, such as parent-infant bonding and being confident in the parental role, can also be improved. Therefore, the overall aim of this study is from a parent’s perspective identifying nature, content, value, and impact of unscheduled conversations among parents and nurses and how these conversations inform planning infant care and involvement in caring for the infant in order to empower parents.

METHODS

Study design

A descriptive qualitative study was conducted with parents who had infants cared for at the NICU and who experienced nature, content and value of bedside conversations with nurses of the NICU. It was explored how these unscheduled conversations informed parents in planning infant care and involvement when they cared for their infant in order to be empowered¹⁸.

Population and domain

The target population were parents who had an infant cared for at the NICU at the Utrecht University Medical Centre, The Netherlands. A convenience sample was applied for this study¹⁸, so variation among parents was guaranteed. Parents experienced with unscheduled conversations were asked to participate. Parents were eligible for participation if they met the following requirements and were a) aged 18 years or older b) had access to the internet and c) had an infant admitted to the NICU for at least one week and spoke either Dutch or English. Practice showed that parents experienced a peak stress point in the first week of their infant being admitted to the NICU, so inclusion before one-week admission was ethical not appropriate. Parents were excluded if they were unable to provide consent, or if they had an infant with a prognosis of imminent death.

Procedures

Recruitment took place at the NICU of Utrecht University Medical Centre Utrecht, The Netherlands. Eligible parents were screened using the inclusion criteria. The principal investigator A. van den Hoogen (AH) and a neonatal nurse that worked at the NICU asked parents to participate. Both were trained in the study protocol. Parents who expressed interest in the study received a study information letter and an informed consent form (ICF). Parents were given 3-5 days to decide about participation. AH provided parents the opportunity to ask questions about the study. After AH received the signed informed consent form, the executing investigator C. van Noort (CN) contacted parents via telephone and arranged an interview appointment.

Data collection

Prior to data collection, CN visited the NICU to become familiar with this particular study site.

Semi-structured web-based interviews were conducted by CN between the period of March and May 2021. A videoconferencing software application was used due to the COVID-19 pandemic.

An interview guide based on existing evidence from research^{7,14,16-17} and expert opinions (AH) facilitated the interviews. Topics included the following: 1) issues nurses and parents

discussed bedside, 2) how unscheduled conversations contributed to involvement in infant care and how infant care was planned, 3) how unscheduled conversations contributed to parental needs during admission and 4) how unscheduled conversations contributed to parental empowerment. All interviews started with, “Which non-medical issues do nurses discuss when you are present at the bedside of your infant?”

The interview guide was adapted based on new insights gained during data collection and after a consensus was reached between CN and AH. Appendix A contains the interview guide.

Interviews were audio recorded and lasted on average 25 minutes (min = 15, max = 52). CN wrote field notes for the overall appearance of parents and their non-verbal behavior¹⁹. No repeat interviews were necessary. The baseline characteristics were collected by CN at the start of each interview.

Four parents that were approached for this study refused to participate due to their own physical health. There were two dropouts for an unknown reason.

Data collection ended when saturation was reached, meaning the participants did not provide any additional insights²⁰.

Data analysis

Data collection and analysis were performed simultaneously. The six phases of thematic analysis by Braun and Clarke²¹ were conducted: a) familiarizing with data, b) generating initial codes, c) searching for themes, d) reviewing themes, e) defining and naming themes and f) producing the report²¹. The thematic analysis had an inductive approach at semantic level since there was no relevant literature on this topic. No pre-existing coding framework was used. In the first phase, CN transcribed all interviews ad verbatim²¹. Transcripts were uploaded onto NVivo 12. All transcripts were read repeatedly by CN and AH to familiarise themselves with the content²¹. In the second phase, individual narratives of parents were coded by CN and AH independently, so that credibility was ensured²¹. In the third phase, the different codes were systematically coded into themes and subthemes²¹. These themes and subthemes were refined in phase four, by considering whether the codes for each theme formed a coherent pattern. Validity of the themes was considered in relation to the data set²¹. In the fifth phase, themes were defined²¹. The essence of what each theme was about and what aspect of the data each theme captured was defined²¹. In the final phase, the report was produced using the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines^{21,22}.

CN and AH both reviewed the codes and themes to increase validity of the analysis and reduce any potential researcher bias.

Ethical issues

The study was conducted according to the principles of the Declaration of Helsinki 2013. Personal data was handled in accordance with EU General Data Protection Regulation. Parents cannot be identified by the data. A list containing the subject identification codes was used to link the data to the parents and was kept on a secured data server. Ethical approval for the study was received from the University Medical Center Utrecht Research Ethics Committee. Participation in the study did not cause risks or provide any benefits to parents.

RESULTS

Participants

A total of twelve parents were interviewed, including ten mothers and two fathers. The mean age of parents was 33 years (min = 22, max = 48). All of the parents had a partner. Ten parents had a higher educational level. The gestational age of the fourteen infants ranged from 25-39 weeks (median = 28). Infants' birthweight ranged from 630–3435 gram (median = 1145). The length of hospital admission ranged from 3-16 weeks (median = 7). The characteristics of the parents and their infants are presented in Table 1.

Table 1: Characteristics of parents and premature infants

Order of presentation of findings

In general, parents cited that they were given information about their infant's medical condition. Parents also heard if their infant slept and ate well, and they were informed about issues relating to basic care. However, to answer the research question, further insight was required to determine which non-medical issues parents heard and discussed bedside.

The analysis resulted in two main themes and six subthemes. The main themes included: 1) searching for trust and 2) growing into the parental role.

Searching for trust

All parents indicated that they built a relationship of mutual trust with nurses from the first day their infant was admitted to the NICU until discharge. Parents searched for trust in medical and non-medical issues they heard when they were bedside at their infant. Once parents gained this feeling of trust at a social and emotional level, they expressed their thoughts related to the admission of their infant and talked about their personal life and well-being with nurses when they were present bedside.

a. Talking about emotions

Parents described that they talked about their feelings and emotions which were related to their infant's situation. Feelings of sadness, fear and insecurity due to the premature birth of their infant were discussed bedside. Parents also expressed the many questions they had regarding their infant's health when they were bedside; questions which made them emotional sometimes. Parents cited they heard reassuring words from nurses about their infant's current

condition which made them feel more at ease. Parents also heard from nurses they could discuss their emotional well-being with social work if they wanted to.

And at that moment she also noticed we were very upset, a lot happened the week before, and at that moment she acknowledged our feelings, she noticed my feelings, and she said: well, I see it really hurts your feelings, it is a tough situation... so she gave a kind of recognition to my feelings, and she also asked if there was anything she could do for us.

[Mother, P05]

Some parents indicated they did not talk about their emotional well-being with nurses when they were bedside at their infant. They did not feel connected with nurses or they discussed their emotions with their partner, family or friends.

b. Providing comfort

All parents described that nurses provided them comforting words when they experienced stressful moments at their infant's bedside. These were the moments when their infant's health deteriorated while they were bedside. Parents cited they got comforted by nurses as they heard what was going on at that moment regarding their infant and the cause of deterioration. Afterwards, nurses told parents not to worry too much as their infant's health had stabilized again. In general, parents heard their infant was well monitored and they could relax. Parents heard they could always contact the unit if they had any questions or needed to talk with somebody of the staff.

I was feeling so emotional at such a moment, I could only cry, they noticed that... they then talked about our infant's medical condition, well, they told what happened and why it happened, just to try to reassure us. [Mother, P04]

c. Having chit-chats

Parents cited that they talked about their personal life with nurses when they were at their infant's bedside. Nurses asked parents about their home- and family situation, their jobs, their pregnancy and leisure activities during free time. When parents talked about the nurses or their own personal life, it distracted them from their infant's situation for a moment. Parents indicated this provided them the opportunity to mentally relax. One mother described that these chit-chats with nurses became her social life during the period their infant was admitted at the NICU.

We have had a lot of babysitting problems, an au-pair who left just after I gave birth, we also thanked a babysitter after three days for her babysitting activities, and she sued us for ending her contract, which she did not had, these are the things I discussed, it became a bit of my daily, I mean, I was there twice a day, I did not do many other things, so I shared things like that. [Mother, P05]

Growing into the parental role

All parents indicated that they heard from nurses which skills they needed to develop, so that they could take care of their infant during admission at the NICU. Nurses took parents along in the process of taking care when they were at their infant's bedside; parents heard and discussed these practical issues with nurses. This strengthened parents in getting control over their infant and to take care for their infant independently. As a result, parents indicated, by acting this way, they became empowered in their parental role.

d. Being empowered by getting self-confidence

All parents cited that they heard from nurses how to perform the practical issues related to basic care as cleaning or feeding their infant. They also heard from nurses that the basic care of their infant could be provided best by parents themselves as it stimulates interaction and bonding with their infant. Parents indicated that they heard encouraging words from nurses about how they performed the basic care which gave them self-confidence. Parents indicated they became independent in taking care of their infant at the NICU.

They said things like: you did this very well or hey it looked really good what you were doing, they also talked via our son like “Yes, mommy and daddy are taking good care of you”, you know, all these small things, I was never aware of that, but they did say it and it definitely made my self-confidence grow and influenced my thoughts as a parent, it made me think okay it is going well, you know, we can do this too. [Mother, P03]

Parents indicated that they heard that nurses cared about them as a parent. Parents heard that it was important to take good care of themselves during admission of their infant at the NICU. Parents discussed they felt anxious or guilty when they went home and took time for themselves. Parents heard the importance of creating some leisure to remain strong in being there for their infant.

e. Tuning and collaborating in caring for the infant

Parents and nurses discussed bedside in which order the basic care needed to be provided. At the beginning of the admission, parents heard from nurses possible orders of these activities. After a couple days, parents heard from nurses they needed to decide how to provide basic care and in which order, as they knew their infant best. Nurses controlled the situation when parents provided care for their infant. This controlment changed in letting go of parents once nurses experienced parents were capable of providing care independently.

If my son needed a new IV or something, they always discussed that with us, they also thought about the other things we wanted to do with him during the visitation block. They asked us; okay, you want to do the kangaroo care too, shall we first do that and then change his diaper and flush his belly, or shall we first flush his belly and then do the kangaroo care, what do you think that's best for him? [Mother, P03]

Parents cited that once they became empowered in their parental role, they discussed upcoming questions about their infant's treatment plan while they were bedside. Parents expressed their thoughts or doubts about decisions regarding treatment. One mother cited she observed their infant's appearance and discussed abnormalities of their infant's head to make nurses aware of a possible birth defect. Another mother, also a professional who practiced medicine, indicated that all decisions regarding treatment first needed to be discussed with her before they could be performed by a nurse.

I discussed everything I thought that was different or should be different, so at a certain point they wanted to check my infant's blood sugar level, I didn't understand why, I thought why we need to check the blood sugar level, so I said; you're not going to collect blood until I know why, so we waited till the next morning. [Mother, P05]

One father described he felt frustrated over a nurses' abilities as he experienced some accidents with his infant during admission at the NICU. As he became empowered in his parental role, he acted as an advocate for his infant and asked for a conversation with the responsible nurse to clarify this.

But then we went to the nurse, coincidental the student nurse who took care of our son and was involved by the accidents, and then we said; okay we need to get this of our chest, a number of things happened, and we wonder why. [Father, P08]

DISCUSSION

This study identified the content and value of bedside conversations among nurses of the NICU. It was explored how these conversations informed parents in planning infant care and involvement when they cared for their infant in order to be empowered. Parents searched for trust in medical and non-medical issues they heard when they were bedside at their infant. After they gained this feeling of trust, parents and nurses talked about emotions and had chit-chats about personal lives. Nurses also provided parents words of comfort. Parents grew into the parental role as they heard which skills they needed to develop, so that they could take care of their infant. This gave them self-confidence in the care they provided for their infant. Parents heard that they were collaborating in caring for their infant and as a result, parents became in control over their infant.

Our study showed that parents searched for trust in issues they had heard bedside regarding their infant, to build a relationship of trust with nurses. Hassankhani et al.²³ indicated that parents observe nurses' behaviour during bedside conversations which influenced and contributed to their perceptions of trustworthiness²³; this resonated with present study findings.

Another finding of our study was about parents who talked about their emotions. Our study revealed that parents discussed their fear and insecurity with nurses about their infants admission at the NICU, which made them feel more at ease. Brødsgaard et al.²⁴ confirmed that parents feel safe when their feelings, emotions and experiences are discussed with and acknowledged by nurses²⁴. However, a minority of parents that were included in our study, indicated they did not share their feelings bedside if they did not feel connected with the nurses. It was also shown that a parent-nurse relationship developed when nurses fulfilled the parents' practical and emotional needs during bedside conversations.

Another finding revealed that parents heard comforting words from nurses when they were bedside at their infant, which reassured them at stressful moments at the NICU. These findings are in line with findings of Bry and Wigert²⁵, which indicated that communicating hopeful words that conveyed empathy, affected parents deeply and helped to reassure them²⁵.

Chit-chats between nurses and parents made parents feel relaxed and familiar whilst they were bedside at their infant, which resonated with other study findings by Fenwick et al.²⁶ Nevertheless, Fenwick et al.²⁶ also described that these chats are used by nurses as a strategy to engage parents in infant care²⁶. It can be questioned if these chats took place as part of their nursing role, the nurses' personal interest or both.

Parents who had grown into the parental role was another important finding in our study. Our study showed that nurses provided parents with encouraging words about interacting and taking the lead in decisions regarding their infant. Brødsgaard et al.²⁴ indicated this in a systematic review as essential so that parents could develop their abilities in infant

care, their competencies and grow into the parental role²⁴. Our study revealed that it then became a natural progression for parents to be able to make appropriate decisions regarding their infant's care, which was also described by Brødsgaard et al.²⁷. Fegran et al.²⁸ indicated it is then possible for nurses to withdraw their close support and enhance parents independence²⁸, empowerment and control regarding their infant²⁴, which resonated with present study findings. However, our study showed, that whilst parents cared for their infant at the NICU, they felt guilty about taking care of themselves. Parents did not realise the need to remain strong, in order to be able to take care of their infant during admission and after discharge. After discharge, parents must remain strong to continue their parental role independently, without nursing assistance. Current study findings showed parents were not aware of this importance.

This study had some limitations. Interviews were difficult to schedule given the many impressions parents had regarding their infant's admission. Also, not all parents were interviewed during admission of their infant at the NICU. To minimise potential recall bias, these parents were interviewed within one week of their infant's discharge. No member checks were performed, as the majority of parents indicated no need or time available to read the transcript, as their days were too busy visiting the NICU. It can be debated whether this affected trustworthiness of the study. A strength of this study contained the trustworthiness, which was enhanced by researcher triangulation. Fathers and a deviant case were included which strengthened the results of this study.

Future directions for research include observational methods of the unscheduled conversations, as this could provide a deeper insight into the content and nature of these conversations. An implication for practice results in the importance of nurses creating parental awareness regarding self-care during admission, to remain strong in providing care for their infant. Also, nurses should become aware with regards to the value and importance of unscheduled conversations. Further research is needed to determine the strategies of creating this awareness.

CONCLUSION

Parents established a relationship with nurses as they searched for trust in medical and non-medical issues they heard and discussed bedside. Parents heard words of encouragement and support which provided them the opportunity to collaborate in providing infant care and make decisions regarding their infant. As parents had unscheduled conversations, they became independent, empowered and in control over their infant.

REFERENCE LIST

- (1) Blencowe H, Cousens S, Chou D, Oestergaard MZ, Say L, Moller AB et al. Born Too Soon: The Global Action Report on Preterm Birth. Chapter 2 – 15 million preterm births: priorities for action based on national, regional and global estimates. World Health Organization. May 2012. New York.
- (2) Howsen C, Kinney M, Lawn J. The Global Action Report on Preterm Birth. Chapter 1 – Preterm birth matters. World Health Organization. May 2012. New York.
- (3) Lawn JE, Davidge R, Paul V, von Xylander S, de Graft Johnson J, Costello A et al. Born Too Soon: The Global Action Report on Preterm Birth. Chapter 5 – Care for the preterm baby. World Health Organization. May 2012. New York.
- (4) Madrigal VN, Carroll KW, Hexem KR, Faerber JA, Morrison WE, Feudtner C. Parental decision-making preferences in the pediatric intensive care unit. *Pediatric Critical Care* 2012;40:2876-2882.
- (5) Weiss EM, Barg FK, Cook N, Black E, Joffe S. Parental Decision-Making Preferences in Neonatal Intensive Care. *The Journal of pediatrics* 2016 Dec;179:36-41.e3.
- (6) Payot A, Gendron S, Lefebvre F, Doucet H. Deciding to resuscitate extremely premature babies: How do parents and neonatologists engage in the decision? *Social science & medicine* (1982) 2007 Apr;64(7):1487-1500.
- (7) Wigert H, Dellenmark Blom M, Bry K. Parents' experiences of communication with neonatal intensive-care unit staff: an interview study. *BMC pediatrics* 2014 Dec 10;14(1):304.
- (8) Abela KM, Wardell D, Rozmus C, LoBiondo-Wood G. Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review. *Journal of pediatric nursing* 2020 Mar;51:21-31.
- (9) Henner N, MD, Boss, Renee D., MD, MHS. Neonatologist training in communication and palliative care. *Seminars in Perinatology* 2016;41(2):106-110.
- (10) Jee RA, Shepherd JR, Boyles CE, Marsh MJ, Thomas PW, Ross OC. Evaluation and comparison of parental needs, stressors, and coping strategies in a pediatric intensive care unit. *Pediatric Critical Care Medicine* 2012;13:e166-e172.
- (11) Orzalesi M, Aite L. Communication with parents in neonatal intensive care. *The journal of maternal-fetal & neonatal medicine* 2011 Oct;24(S1):135-137.

(12) Michelson K, Clayman ML, Ryan C, Emanuel L, Frader J. Communication During Pediatric Intensive Care Unit Family Conferences: A Pilot Study of Content, Communication, and Parent Perceptions. *Health communication* 2017 Oct 3;;32(10):1225-1232.

(13) October TW, Dizon ZB, Roter DL. Is it my turn to speak? An analysis of the dialogue in the family-physician intensive care unit conference. *Patient education and counseling* 2018 Apr;101(4):647-652.

(14) Vos MA, Bos AP, Plotz FB, Heerde M, Graaff BM, Tates K, et al. Talking with parents about end-of-life decisions for their children. 2015 Feb 1,.

(15) Fumagalli LP, Radaelli G, Lettieri E, Bertele' P, Masella C. Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. *Health policy (Amsterdam)* 2015 Mar;119(3):384-394.

(16) Fernandez Medina IM, Granero-Molina J, Fernandez-Sola C, Hernandez-Padilla JM, Camacho Avila M, Lopez Rodriguez, M D M. Bonding in neonatal intensive care units: Experiences of extremely preterm infants' mothers. *Women Birth* 2018 August 01;31(4):325-330.

(17) Guillaume S, Michelin N, Amrani E, Benier B, Durrmeyer X, Lescure S, et al. Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. *BMC Pediatr* 2013 February 01;13:18-18.

(18) Holloway I, Galvin K. *Qualitative Research in Nursing and Healthcare*. 4th ed. UK: Wiley Blackwell; 2017.

(19) Phillippi J, Lauderdale J. *A Guide to Field Notes for Qualitative Research: Context and Conversation*. *Qualitative health research* 2017 Apr 5;;28(3):381-388.

(20) Guest G, Bunce A, Johnson L. How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field methods*. 2006;18(1):59–82.

(21) Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006 Dec 1;;3(2):77-101.

(22) Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care*. 2007;19(6):349–557

(23) Hassankhani H, Negarandeh R, Abbaszadeh M, Craig JW, Jabraeili M. Mutual trust in infant care: the nurses and mothers experiences. *Scand J Caring Sci* 2020 September 01;34(3):604-612.

(24) Brodsgaard A, Pedersen JT, Larsen P, Weis J. Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis. *J Clin Nurs* 2019 September 01;28(17-18):3117-3139.

(25) Bry A, Wigert H. Psychosocial support for parents of extremely preterm infants in neonatal intensive care: a qualitative interview study. *BMC Psychol* 2019 November 29;7(1):76-4.

(26) Fenwick J, Barclay L, Schmied V. 'Chatting': an important clinical tool in facilitating mothering in neonatal nurseries. *J Adv Nurs* 2001 March 01;33(5):583-593.

(27) Brodsgaard A, Zimmermann R, Petersen M. A preterm lifeline: Early discharge programme based on family-centred care. *J Spec Pediatr Nurs* 2015 October 01;20(4):232-243.

(28) Fegran L, Fagermoen MS, Helseth S. Development of parent-nurse relationships in neonatal intensive care units--from closeness to detachment. *J Adv Nurs* 2008 November 01;64(4):363-371.

TABLES AND FIGURES**Table 1***Characteristics of parents and preterm infants (n=12)*

Characteristic	n OR M (median)
Parents' sex	
Male	2
Female	10
Partner	
Yes	12
No	0
Age (year)	
Range (mean)	22-48 (33)
Parents' educational level	
Low	1
Intermediate	1
High	10
Gestational age (week)	
Range (median)	25-39 (28)
Infants' birth weight (g)	
Range (median)	630-3435 (1145)
Length of hospital admission (week)	
Range (median)	3-16 (7)

APPENDIX A

Interview guide

Demographic characteristics	<ul style="list-style-type: none"> • Sex • Age • Partner • Level of education • Gestational age • Birth weight
Exploring nature and content of unscheduled conversations	<ul style="list-style-type: none"> • Which non-medical issues do nurses discuss when you are present at the bedside of your infant? • Which non-medical issues do you discuss with nurses when you are bedside at your infant? • What do you hear from nurses when you are bedside at your infant?
Exploring value and impact of unscheduled conversations related to parental needs	<ul style="list-style-type: none"> • What do you need as a parent when your infant is admitted to the NICU? <ul style="list-style-type: none"> - Do the unscheduled conversations contribute to these needs? - How? - If not, could you tell me more about this? • How do you feel about nurses paying attention to you as a parent during admission of your infant? • Value of unscheduled conversations
Exploring how unscheduled conversations inform planning infant care and involvement in caring for the infant in order to be empowered	<ul style="list-style-type: none"> • How do the unscheduled conversations with nurses contribute to you feeling involved in the care of your infant? • How do the unscheduled conversations with nurses influence the way your infant receives care? <ul style="list-style-type: none"> - How? - If not, could you tell me more about this? • Do you feel more confident in caring for your infant by having unscheduled conversations? <ul style="list-style-type: none"> - How? - If not, could you tell me more about this?
End	<ul style="list-style-type: none"> • Are there any issues related to the unscheduled conversations we have not discussed yet but are important to know?