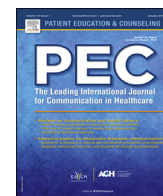




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# Parents' needs and perceived gaps in communication with healthcare professionals in the neonatal (intensive) care unit: A qualitative interview study

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### ABSTRACT

**Objective:** To explore parents' needs and perceived gaps concerning communication with healthcare professionals during their preterm infants' admission to the neonatal (intensive) care unit (NICU) after birth.

**Methods:** Semi-structured, retrospective interviews with 20 parents of preterm infants (March 2020), admitted to a Dutch NICU (level 2–4) minimally one week, one to five years prior. The interview guide was developed using Epstein and Street's Framework for Patient-Centered Communication. Online interviews were audio-taped and transcribed verbatim. Deductive and inductive thematic analysis was performed by two independent coders.

**Results:** Communication needs and gaps emerged across four main functions of NICU communication: Building/maintaining relationships, exchanging information, (sharing) decision-making, and enabling parent self-management. Communication gaps included: lack of supportive physician communication, disregard of parents' views and agreements, missing communication about decisions, and the absence of written (discharge) information.

**Conclusion:** This study improves our understanding and conceptualization of adequate NICU communication by revealing persisting gaps in parent-provider interaction. Also, this study provides a steppingstone for further integration of parents as equal partners in neonatal care and communication. **Practice implications:** The results are relevant to practitioners in the field of neonatal and pediatric care, providing suggestions for tangible improvements in NICU care in the Netherlands and beyond.

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## 1. Introduction

Preterm birth (before 37 weeks' gestation) occurs in 15 million infants annually, affecting approximately 1 in every 10 newborns globally and adding considerably to the global burden of disease [1,2]. Preterm infants are prone to high morbidity and mortality and are therefore usually admitted to a neonatal (intensive) care unit (NICU), where highly specialized medical care can be provided [3].

Preterm birth not only affects infants' health, but is also associated with higher stress levels in parents [4]. Parent-infant

separation following an unexpected preterm delivery can be traumatic to parents and is linked to postpartum depression and post-traumatic stress [5]. Parents often feel uncertainty and a loss of control concerning their infants' wellbeing [6,7]. They also experience feelings of anxiety, frustration, guilt, and helplessness during and following their infant's admission to the NICU [8], which can potentially negatively influence their transition into parenthood [9,10].

The Family Integrated Care (FiCare) model, which was initially developed in Canada by a team of parents and healthcare professionals to improve infant and parent outcomes [11,12], is an advancement of family-centered care [13]. Within FiCare, parents are actively involved as primary caregivers and they are integral and equal members of the NICU team during infant hospitalization. They are encouraged to provide their infant's care as much as they feel comfortable, to actively participate in ward

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rounds, to chart their infant's growth and progress and to participate in clinical decisions about their infant's care with the medical care team. FICare includes four pillars focusing on: (1) the environment of NICU wards to ensure prolonged parental presence [14,15], (2) staff education on parent involvement in care and tools to coach and support parents [16–18], (3) parent education at the bedside and during small group sessions to transfer medical knowledge and foster parents' confidence and skills [19], and (4) providing psychosocial support to parents [17,20]. Within the context of FICare, adequate parent-provider communication is assumed to be pivotal across these pillars (Table 1).

Several studies have explored parents' experiences with care in the NICU, including the interaction with providers [21–24]. In two systematic reviews and meta-syntheses, we found that both parents and providers deem adequate communication important to achieve optimal parent-staff relationships, information exchanges, decision-making, and parent self-management [25]. Communication can affect parent-related outcomes of NICU care, including parents' coping, medical knowledge, participation in communication and care, empowerment and bonding with their infant, and their satisfaction with care – both negatively and positively [26]. To date, studies have not investigated the remaining communication *needs* and *gaps* parents perceive, while concurrently linking these to the different functions of communication in neonatal care. This study seeks to address and explore this hiatus in the literature.

## 2. Methods

### 2.1. Study design

Semi-structured, retrospective interviews were conducted to identify parents' needs as well as their perceived gaps concerning interactions with staff, across various functions of interpersonal communication in the NICU. To develop the interview guide, Epstein and Street's Framework for Patient-centered Communication in Cancer Care was used [27,28]. Interview questions focusing on parents' communication experiences in the NICU were formulated, divided by the communication functions proposed by Epstein and Street [28]: (1) providing information, (2) gathering information, (3) decision-making, (4) enabling disease- and treatment-related behaviors, (5) fostering relationships, and (6) responding to emotions. See Fig. 1 (full guide, in Dutch, available

upon request). The interview guide was pilot tested with a former NICU parent and founder of Kleine Kanjers, a Dutch parent support platform (information, blog, and shop, see [www.kleinekanjers.nl](http://www.kleinekanjers.nl)) that has a broad social media outreach among parents of preterm infants. Following the pilot, only minor changes were made to the protocol.

### 2.2. Sample

Parents of preterm infants (born < 37 weeks' gestation) were eligible for participation if they had been admitted to a Dutch level 2–4 NICU for at least one week, one to five years ago [3]. This limit was set in consultation with the ethical committee, to ensure adequate recall of parents' communication experiences in the NICU while, simultaneously, avoiding causing parents unnecessary stress by reflecting on traumatic memories too soon after discharge [29]. Rather than determining parents' experiences during or immediately after admission, this study also purposefully sought to map parents' lasting views on communication – even years after hospitalization. Infants had to have been admitted in the NICU for over a week to ensure sufficient exposure to interpersonal communication with both nursing staff and neonatologists. Interviews were held in Dutch.

### 2.3. Procedures

Participants were recruited in collaboration with Kleine Kanjers. Following the online announcement for study participation, 62 parents registered to be interviewed. Parents were interviewed in order of registration and did not receive any incentive for participation. Interviews were conducted until data saturation was reached, which was the case after 20 interviews.

All interviews were held by the first author (EL) in April–May 2020, via an online video conferencing tool. Parents did not know the interviewer beforehand. Interviews were audio-recorded with an external voice recorder and field notes were taken. All interviews lasted between 35–60 min. Interviews were transcribed verbatim and stored in an online secured environment solely accessible to the research team. All participants were informed about study procedures and provided written and verbal informed consent. Interview summaries were sent to participants for a member check. Two participants responded for additions.

**Table 1**  
Participant Characteristics.

#	Gender	Age	Infant gestational age	Infant age <sup>a</sup>	Duration NICU stay	Duration NCU stay	Extra notes
1	Female	28	35 weeks	3.5 years	3 weeks	2,5 weeks	
2	Female	32	29 weeks, 4 days	3 years	1 week	6 weeks	
3	Female	36	26 weeks, 5 days	5 years	8 weeks	4 weeks	
4	Female	29	24 weeks, 5 days	3.5 years	12 weeks	4 weeks	
5	Female	32	29 weeks	1 year	2 weeks	12 weeks	
6	Male	35	26 weeks, 2 days	4.5 years	13 weeks	4 weeks	
7	Female	32	27 weeks	3 years	14 weeks	None	
8	Female	30	32 weeks, 2 days	2 years	2 weeks	5 weeks	
9	Female	38	27 weeks, 4 days	Unknown	7 weeks	5 weeks	Twins
10	Female	33	30 weeks	2.5 years	2 weeks	6,5 weeks	Twins
11	Female	34	28 weeks, 4 days	3.5 years	7 weeks	12 weeks	
12	Female	Unknown	35 weeks	3.5 years	2 weeks	None	
13	Female	36	27 weeks, 4 days	4.5 years	7 weeks	6 weeks	
14	Female	34	26 weeks, 6 days	2 years	5 weeks	6 weeks	
15	Female	34	29 weeks, 3 days	4 years	4 weeks	8 weeks	
16	Female	37	29 weeks, 4 days	3 years	1,5 weeks	3 weeks	
17	Female	35	31 weeks	4 years	3 weeks	5 weeks	
18	Female	35	28 weeks	Unknown	2 weeks	8 weeks	
19	Female	31	24 weeks, 6 days	1.5 years	12 weeks	4 weeks	Twins
20	Female	31	33 weeks, 6 days	3 years	1,5 weeks	4 weeks	

<sup>a</sup> Age at time of the interview, rounded off to half a year.

Functions of patient-provider communication	Example interview questions
Providing information	How were you informed about your child's situation by the doctors/nurses during hospital admission? To what extent did you understand what healthcare providers communicated during this period?
Gathering information	How were you enabled to provide information to doctors/nurses yourself? How did the providers respond to your ideas? Did it feel like they took you seriously?
Decision-making	Could you describe times when decisions had to be made? Can you give an example of a decision that you took? What did you think of the attitude of the doctors/nurses?
Enabling disease & treatment related behaviour	To what extent were you involved by your provider to provide certain care to your child? How were you prepared for care provision after discharge?
Fostering the relationship	Could you describe your relationship with the doctors/nurses at the hospital? What could be better in terms of communication when it came to these relationships?
Responding to emotions	How did your child's providers deal with your emotions at the hospital? What could be improved in terms of communication when it came to providers' responses to your emotions?

Fig. 1. Example questions from the interview guide, based on Epstein and Street's Framework for Patient-centered Communication [27,28].

We used the Consolidated criteria for reporting qualitative studies (COREQ) checklist [30]. The study procedures comply with the Declaration of Helsinki and were approved by the Science and Ethics Committee of the Vrije Universiteit Amsterdam, The Netherlands (VCWE-2019-132). The Medical Ethical Committee of the Amsterdam UMC (location VUmc) ruled that the study is not subject to the Medical Research Involving Human Subjects Act (2019.596).

#### 2.4. Data analysis

Transcripts were analyzed using deductive and inductive thematic analysis [31]. First, two members of the research team (EL, NL) familiarized themselves with the data by (re)reading all transcripts. This provided insights in the similarities and differences between participants' communication experiences. Then, they independently coded five interview transcripts. Epstein and Street's Framework was used to deductively distinguish between the functions of communication, but new functions could also emerge inductively [28]. Subsequently, communication needs and gaps identified by parents were coded inductively, within each function of communication. Following the first coding round, codes and analyses were discussed and a codebook was established, allowing for coding of the remaining transcripts. Analyses were discussed in the research team, which included neonatologists and researchers experienced with FiCare (AvK, NvV). NL assumed a dual role of investigator-parent representative. An expert panel was instated to reflect on the methods and findings of the overall project, to detect and minimize potential biases due to these personal and professional experiences.

### 3. Results

#### 3.1. Participant characteristics

The vast majority of participants were female (N = 19/20, 95%). Participants were aged 28–38 years (mean = 31.6) and lived across

the Netherlands. Infants had been admitted to 12 different NICUs. For most parents (N = 17), their preterm infant was their first-born. Three parents had multiple preterm infants and reflected on their most recent NICU experience. Infants, 17 singletons and 3 sets of twins, had an average gestational age of 28 weeks and 6 days (range 24 weeks and 5 days to 35 weeks). They were admitted on average 76.2 days (range: 14–133 days) in the NICU, of which 39.6 days (range: 7–98 days) in a level 3 or 4 facility (intensive care) and 36.7 days (range: 0–84 days) in a level 2 ward (medium-high care).

#### 3.2. Perceived needs and gaps across communicative functions

The analytic process revealed four main functions of communication in NICU settings: (1) Building and maintaining relationships, (2) exchanging information, (3) (sharing) decision-making, and (4) enabling parent self-management. Notably, these four main themes form a contextualization and refinement of the Framework for Patient-centered Communication [27,28] applied to NICU settings. No new communication functions emerged at the main level compared to Epstein and Street's framework, some were merged. At the sublevel, new themes arose inductively. Similar results were found in two parallel studies by the authors [27,28]. Parents' perceived communication needs and gaps for each of the four communicative functions will be discussed below. In the Appendix, additional quotes per communicative function can be found.

##### 3.2.1. Building and maintaining relationships

The theme *building and maintaining relationships* combines two communication functions distinguished by Epstein and Street [28], namely responding to emotions and fostering relationships. Within the context of NICU communication, it appeared that relationships between parents and providers are built and maintained first and foremost through regulation of parents' emotions and distress and the management of uncertainty (e.g., about infants' prognostics). As such, these themes were clustered.

Overall, parents indicated a high need for professionals to communicate empathy and understanding. Parents wanted to feel

heard and listened to. Parents' desire for emotional support seemed to depend heavily on their infant's medical situation. Whenever infants' health decreased, their need for emotional support increased. Parents who experienced a lengthy hospital stay indicated higher needs for emotional support from staff. Parents who mentioned receiving adequate emotional responses from healthcare professionals, emphasized it had affected their NICU experience positively – even in the long-term:

*We had one nurse, I recall, she was an incredibly sweet woman and she was also constantly concerned with how we were doing, and she also just said 'I understand that you are having a hard time', you know, and that really stayed with us – Female, 28; infant, 35 weeks*

Parents were generally quite satisfied with their relationships with nursing staff; however, they expressed a distant relationship to their infants' doctors. Neonatologists' busy schedules inhibited frequent interaction. When doctors focused solely on information-provision during communication and did not take sufficient time to attend to parents' feelings and anxiety concerning their child's preterm birth, this hindered establishing a trusting relationship:

*I mean, I knew it was busy but they still do not have the right to drop heavy news just like that and then say 'oh, by the way, I don't have any time right now to talk about it but we will do so tomorrow'. Well, you just cannot do that and, for me, that was really like . . . I don't want to talk to you anymore, it's just over – Female, 32; infant, 29 weeks*

Notably, disagreements between parents and healthcare professionals appeared to be common and occurred across NICU levels and regardless of infants' medical conditions. Conflicts occurred when staff members disregarded parents' views on their infants' care, deviated from agreed-upon plans in non-acute settings, provided inaccurate care (e.g., switching breast milk with another infant's milk), or made a medical mistake (e.g., misdiagnosis). In case of conflict, the parent-provider relationship was hampered severely. Conflicts between parents and staff often resulted in requests from parents to have a staff member removed from care for their infant and sometimes led them to consider taking legal action:

*She [healthcare professional] just did not understand us, and she did not listen, and she was actually just working against us. So, we requested to have her near us as little as possible – Female, 32; infant, 32 weeks*

### 3.2.2. Exchanging information

The second theme that emerged was *exchanging information*. Much like in Epstein and Street's Framework [28], this theme could be subdivided into *information provision by professionals* and *sharing by parents*. In order for parents to understand their infants' medical situation, medical staff must first provide them with adequate information. Parents strongly emphasized a need for communication that is clear, calm, and comprehensive – particularly upon admission to the NICU:

*Yes . . . what I just find important is the communication when you arrive there, that they then tell everything clearly . . . also the most stupid things, just explain them, because as a mother everything is complete chaos and then it is important to get everything explained – Female, 33; infant, 30 weeks*

When parents experienced insufficient communication or when communication was overly complex due to medical jargon, parents tended to search for answers online rather than asking for clarifications. Parents indicated a strong preference for shared, written information to complement interpersonal exchanges. This could foster

parents' understanding and knowledge concerning their infant. However, parents felt such written information was often lacking:

*A joint file where you have access to, no that was not available back then. But I would have liked it, if I could have re-read some things on paper – Female, 35; infant, 31 weeks*

Parents also expressed an increasing need throughout their NICU trajectory to share their own knowledge and information about their infant's condition with healthcare professionals. This view was less pronounced in level 3 or 4 units, but became particularly prominent in level 2 units. While parents experienced intensive care as (too) complex, requiring medical expertise, they felt they could contribute meaningfully to improving their infant's wellbeing during admission to a high or medium care ward. As parents consistently had spent a significant amount of time with their infant at that stage, they felt they possessed unique knowledge that could be important for the care process. Nonetheless, parents experienced a gap between their confidence in their own views and opinions, and their ability and possibilities to communicate about them with healthcare professionals:

*We do not know much about it, I assume they want the best for the children and so, yes, who are we to say 'we do not want this and we do want this' – Female, 32; infant, 26 weeks*

### 3.2.3. (Sharing) decision-making

The third theme that emerged was *(sharing) decision-making*. This theme could be subdivided into *urgent* and *non-urgent* decision-making. Most parents preferred all *urgent* treatment decisions to be made by medical staff, without requiring their prior consent – particularly in parents' absence. Parents expressed not wanting to waste time on communication in anticipation of an acute in decision in a level 3 or 4 NICU:

*At a certain point, the nurse urgently switched back to an oxygen mask, so she [the infant] had to go back on the ventilator to help her breathing through a tube . . . yeah . . . that was just urgent and then there was no discussion about it and that is fine. You know, that is just fine – Male, 35; infant, 26 weeks*

Some parents explicitly experienced a gap in the communication about these urgent decisions in hindsight. They expressed they needed healthcare professionals to inform them afterwards and to provide reasoning in support of the decisions that were made. If not, they felt unaware of medical procedures that had been performed on their child, hampering parents' trust:

*There were also people [healthcare professionals] who built entire stories around it and then only half of that turned out to be true because it turned out things had gone completely differently or they withheld information and that made me very suspicious – Female, 32; infant, 27 weeks*

Contrarily, all parents demonstrated a need to be included in communication about all *non-urgent* treatment decisions. According to parents, to be included in non-urgent decision-making entails providers explaining the medical situation at hand upfront, talking them through all available options, and asking parents for input. Parents appreciated the feeling of being part of decision-making processes and being allowed to share decisions. When providers communicated clearly, parents often ended up agreeing with providers' recommendations.

### 3.2.4. Enabling parent self-management

Finally, *enabling parent self-management* appeared as a fourth function of communication. This theme is particularly salient as, throughout the NICU trajectory, parents need to become increasingly self-reliant in taking care of their infant, to prepare them for



discharge. *Enabling parent self-management* can be divided into *practical care* and *parent empowerment*.

Parents expressed an explicit need to receive clear explanations and training from nurses on how to provide *practical* care for their infants. They needed to get to know the NICU environment, its procedures and equipment, but also more hands-on practicalities such as how to change their infant's diaper:

*I had no clue in the beginning . . . you just watch the first few times and then all of a sudden they say 'well, maybe you would you like to help a little or at least place your hand on his head' and then eventually you are allowed to change his diaper, to wash his mouth and yes . . . they explain everything very well – Female, 32; infant, 29 weeks*

In addition, parents expressed the need for positive feedback from healthcare professionals to grow confidence as a parent; they felt they needed to be *empowered* in their parental role. Reversely, negative feedback about the way parents provide care (e.g., taking too much time feeding or closing the incubator door too loudly) appeared to be quite common and hampered parents' self-confidence, their willingness to share information, and mental preparedness for their transition to home. Finally, parents often missed information-provision on discharge to home and the first period following hospitalization, which was distressing to them:

*At home everything is different and I really felt insecure. I was not prepared at all and I did not have the entire team of doctors and nurses available anymore – Female, 24; infant, 29 weeks*

## 4. Discussion and conclusion

### 4.1. Discussion

This interview study examined Dutch parents' needs as well as their perceived gaps concerning communication with NICU staff. A systematic, theory-driven approach was used to determine the precise functions of interpersonal communication in the context of neonatal care and to identify parents' corresponding experiences. Providing a contextualized version of Epstein and Street's Framework for Patient-centered Communication in Cancer Care, [28] four analytically separate functions of NICU communication were identified through deductive and inductive analysis of our interview data: (1) Building and maintaining relationships, (2) information exchange, (3) (sharing) decision-making, and (4) enabling parent self-management. These main themes correspond to the findings in two parallel systematic reviews on communication functions, adequacy, and effects in NICU settings [25,26]. The present study lays bare the opportunities to address parents' persisting unmet needs in their interactions with NICU staff, across all functions of communication.

To build and maintain relationships of mutual trust, parents demonstrated a high need for healthcare staff to provide them with emotional support throughout their NICU journey. There is a clear gap between what parents need and what they currently experience in terms of supportive communication from staff. Conflicts between medical staff and parents are common, impacting parents' care experiences negatively. During hospitalization conflicts lead to a decrease in trust and even cause parents to request staff to be removed from their infant's care. This is consistent with previous findings [32]. In the context of cancer treatment, research shows that when trust in healthcare professionals is hampered, patients' fear increases, medical decision making is hindered, and treatment adherence is reduced [33]. These adverse outcomes should be avoided in the NICU.

While *receiving* information from healthcare professionals appears to be particularly important at the onset of a NICU trajectory, providing parents with ample opportunities for *sharing*

information becomes important towards the later stages of hospitalization, especially once the infant's condition has stabilized. This concurs with previous findings [23]. While the relevance of supplementary, written information has been frequently emphasized in NICU settings and beyond [34–36], parents in our study still reported a lack thereof. A noteworthy result from our study is that when (verbal or written) information is inconsistent, missing, overly complex, or jargon-ridden, parents are inclined to search for information elsewhere rather than asking for clarifications. This may negatively affect the quality of information parents receive, and is thus a finding that deserves attention.

Enabling parents to share information, to ask questions, and to voice their opinions is an essential component of FiCare. Yet, our study suggests that parents only deem themselves knowledgeable enough to share their views once their infant is stabilized. In more complex, intensive care settings parents feel *incapable* to share, as they think medical-technical knowledge is a prerequisite for exchanging information with healthcare professionals. Disturbingly, we found that in *non-urgent* settings parents not always feel *allowed* or welcome to share their views. This finding needs further exploration, as proper information-exchanges between staff and parents are valuable across all levels of care and situations and are a prerequisite for shared decision making. The introduction of family-integrated rounds offers opportunities for parents to gain confidence to speak up, ask questions, and build trusting relationships with doctors. Several studies have reported on the (successful) integration of parents as partners in medical rounds [37,38]. However, a mere invitation to medical rounds is not the solution. Parents and professionals need tools and a multidimensional care and implementation model to ensure its success [11].

In terms of decision-making, our study shows that a distinction should be made between *urgent* and *non-urgent* decision-making. Whilst parents want to be informed about acute decisions and the rationale behind them, they do not feel the need to be involved prior to implementation but they do require adequate information in retrospect. When decisions are not immediately urgent (e.g., increasing enteral or oral feeding, CPAP weaning steps, ordering an MRI), parents do want to be involved upfront. According to Weiss et al. (2016) being involved in such decisions enables parents to assume a parenting role [39]. Notably, having a *sense* of being involved in the decision-making process (rather than actively deciding) seems to be sufficient for parents. When they feel involved, they are inclined to agree with, and feel confident about, proposed treatment plans. This also applies when full-blown shared decision-making is impossible, because the situation is acute or when there is only one treatment plan that is medically appropriate. However, when non-urgent decisions are communicated poorly or after implementation, conflict can arise [40]. These findings are interesting as they may, on the one hand, implicate that parents are prone to healthcare providers' implicit persuasion. On the other hand, they may suggest that *shared* decision-making is not necessarily preferred by parents, but that clear and open *sharing* about decision-making (plans) is crucial.

Finally, empowering parents in their role as primary caregivers of their child through communication appears highly important – particularly before discharge. The importance of adequately preparing parents for discharge has been emphasized previously [41–44]. As preterm birth can be distressful for parents, it is pivotal to enable parenting and encourage parents' independence over time. Providers may do so by providing information and involving parents in caretaking activities, such as feeding and diaper changes, and offering discharge education. Yet, parents also have a strong need for positive encouragement about their caregiving capacities during day-to-day communication with staff. Such encouragements seem to be frequently lacking.

The findings should be interpreted in light of some limitations. First, while the sample was relatively heterogeneous and data saturation was achieved, the study included only one male participant. It is possible that additional interviews, for example with fathers or partners would have yielded additional themes [45]. Hence, future studies should specifically focus on including partners as well. Second, it should also be noted that parents actively signed up to participate, thereby inherently inducing motivation bias. More so, the time limits set for participation (1–5 years post hospitalization) may have caused recall bias. However, we were also specifically interested in more long-lasting impressions of NICU communication, rather than during or immediately following admission. Some participants had multiple preterm children. They were asked to reflect on their most recent experience, although we cannot be certain they did. Third, due to the COVID-19 crisis, data collection was conducted online. For purposes of building rapport as well as to optimize (non-)verbal communication between participants and interviewer, real-life interviews would have been favorable. We therefore paid particular attention to gaining participants' trust and allowing them to share their emotions. Fourth, the first author conducted all interviews alone. Data analysis, however, was done with a multidisciplinary research team, including health communication scholars, an investigator-parent representative, and neonatologists which is a strength of the study. Fifth, the present findings are inherently embedded within a Dutch healthcare context and additional interviews beyond Dutch borders could provide additional or other insights.

#### 4.2. Conclusion

This study provides a systematic, qualitative overview of Dutch parents' continued (un)met needs in their communication with NICU staff. While various studies have previously investigated parents' experiences with NICU care, including aspects of parent-provider interaction [21–24], this is one of the few studies to use a theory-driven approach to explore parents' communication experiences across the several functions that communication can have in neonatal care. This approach fits with a desire to conduct both theoretically relevant and data-driven research in health communication. The findings provide a contextualization and refinement of Epstein and Street's Framework for Patient-centered Communication in Cancer Care [28], and thereby contribute towards a systematic conceptualization of communication in the NICU (i.e., a NICU Communication Framework) [25,26]. Furthermore, this study adds to current endeavors to promote the integration of families as equal and irreplaceable members of infants' care teams within NICU settings. The present data show that by building trusting relationships, exchanging correct and sufficient information, engaging parents in all non-urgent medical decisions, and providing parents with the self-confidence to take up their parental role, healthcare professionals can minimize parents' distress and foster the integration of parents in infants' care teams.

#### 4.3. Practice implications

The results of the present study are relevant to scholars and practitioners of health communication, pediatrics/neonatology, and nursing alike. By pointing to existing gaps in parent-provider communication, this study shows that parents' overall experiences of NICU care can still be (further) improved, for instance via education for healthcare professionals and parents, the use of tools to aid joint informed decision-making among parents and professionals, and the implementation of family-centered rounds to include parents' voices. Preferably, the current dogmas that are

present in NICU care culture should be addressed with multidimensional and evidence-based family care practices. The findings provide a tangible starting point for the integration of communication as an important component of Family Integrated Care (FiCare) practices. Above, our results may be used as an inspiration to formulate explicit points for improvement for the communicative interactions between parents and professionals in NICU departments across the Netherlands and beyond.

#### Informed consent

All personal identifiers have been removed or disguised so participants and patients described cannot be identified through the details of the story. All participants have provided written informed consent.

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#### Ethical approval

This study is part of a larger project (IMPACT), which was approved by the Science and Ethics Committee of the Vrije Universiteit Amsterdam and complies with the ethical guidelines of the university (VCWE-2019-132). The project was also submitted for consideration by the Medical Ethical Committee of the Amsterdam UMC, location VUmc. The committee waived the requirement for formal ethical approval as the study is not subject to the Medical Research Involving Human Subjects Act (2019.596).

#### Patient involvement

NL assumed a dual role of investigator-parent representative from inception to completion of the present study, being a mother to a daughter who was born at 26 weeks' gestation. A parent representative and founder of a Dutch parent-support organization for parents of premature infants (Kleine Kanjers) provided feedback on the final version of the manuscript.

#### CRediT authorship contribution statement

**Esther S. Lorie:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing - original draft, Writing - review & editing. **Willem-jan W. Wreesmann:** Formal analysis, Writing - review & editing. **Nicole R. van Veenendaal:** Formal analysis, Writing - review & editing. **Anne A.M.W. van Kempen:** Formal analysis, Writing - review & editing. **Nanon H.M. Labrie:** Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Supervision, Writing - original draft, Writing - review & editing.

#### Declaration of Competing Interest

The authors declare that there are no conflicts of interest.

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lives. We furthermore are grateful to Hanneke de Wit, founder of Dutch parent-support platform Kleine Kanjers, who kindly shared her thoughts on the final version of this manuscript.

## Appendix A. Additional quotes per communicative function

Function	Quotes from interviews
Building and maintaining relationships	What I noticed from the nurses and doctors who did communicate well, was that they were really open and approachable, and they were really involved. With her I felt safe and I remember that she did the things that I also felt like . . . ok, yes, let's do that, because I trust you! It makes that bond so much stronger and so much more normal than if there is a doctor who just comes to tell you that your child is doing shitty . . . just also ask how we are doing and ask 'is there anything I can do for you?'
Exchanging information	She came across as very stressed out and you do not want that of course. You would rather want that, when things are serious . . . that this person, the provider . . . uhm . . . comes across as calm and as if she has everything under control . . . not making things worse. You have to be realistic, but do not act, let's say, as if the world is coming to an end, while there are still other options . . . that's what I think! I think the nurses did provide us with good information, they really included us and took their time for us.
(Sharing) decision-making	Well, if you wanted to decide something, you had to be really clear that you wanted to make the decision, because otherwise you did not end up making that decision. Uhhh . . . well, it was a positive thing that they, the doctors, came to do their rounds and that they discussed everything about [name] and on occasion a pediatrician would ask like 'what is your take on that?' Actually, we really were involved . . . Why they would decide something . . . that was explained to us so well, so that we would agree and, uhhh . . . when they would genuinely yes, were unsure about what to do, they were transparent about that too and then uhhh we would make the decisions together.
Enabling parent self-management	Yes, well let's say the first few times they show it to you and then at a certain point you start yourself and then yes . . . they say what you have to do, let's say, so yes . . . that went really naturally, yes, they explained it really well. It was discussed during the weekly meetings, like how far would you like to go uhhh, you know, and if there were certain things that we thought were scary to do, we could also let them know.

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