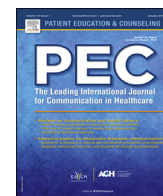




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Review Article

The functions of adequate communication in the neonatal care unit: A systematic review and meta-synthesis of qualitative research

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ABSTRACT

Objective: To assess the main functions of parent-provider communication in the neonatal (intensive) care unit (NICU) and determine what adequate communication entails according to both parents and health professionals.

Methods: A systematic review and meta-synthesis of qualitative research. PubMed, Ebsco/PsycINFO, Wiley/Cochrane Library, Ebsco/CINAHL, Clarivate Analytics/Web of Science Core Collection, and Elsevier/Scopus were searched in October–November 2019 for records on interpersonal communication between parents and providers in neonatal care. Title/abstract screening and full-text analysis were conducted by multiple, independent coders. Data from included articles were analyzed using deductive and inductive thematic analysis.

Results: 43 records were included. Thematic analysis of data resulted in the development of the NICU Communication Framework, including four functions of communication (1. building/maintaining relationships, 2. exchanging information, 3. (sharing) decision-making, 4. enabling parent self-management) and five factors that contribute to adequate communication across these functions (topic, aims, location, route, design) and, thereby, to tailored parent-provider communication.

Conclusion: The NICU Communication Framework fits with the goals of Family Integrated Care to encourage parent participation in infants' care. This framework forms a first step towards the conceptualization of (adequate) communication in NICU settings.

Practice implications: Findings can be used to improve NICU communication in practice, in particular through the mnemonic TAILORED.

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1. Introduction

Each year, approximately 15 million infants are born preterm (before 37 weeks' gestation). This amounts to ten percent of all infants worldwide [1]. Preterm infants are born in the late second or third trimester of pregnancy, when organ systems are not fully developed yet. Preterm infants often need prolonged support, e.g. for breathing, nutrition, and regulation of body temperature. They are prone to complications like infections, intracranial hemorrhages, visual and hearing problems, and severe bowel problems (necrotizing enterocolitis) and their mortality rates are high. In the long-term, preterm infants often need continued medical care, e.g. for lung, cardiac, or neurologic problems, and their risk of delayed psychomotor development is increased. The lower the gestational age, the more support infants need and the higher their risk for long-term adverse outcomes [2–4]. Specialized medical care for preterm infants can be provided in the neonatal (intensive) care unit (NICU). Neonatal care is organized into four different levels (levels 1–4), corresponding to the complexity of care offered (see Table 1) [5].

The NICU is a distressful environment for parents of preterm infants. Along with the concerns parents have for their infant's health and survival, they often experience the NICU as an unfamiliar, dauntingly complex, and frightening environment [6]. Throughout their infants' admission to the NICU, parents interact with various healthcare professionals, including neonatal physicians, neonatal nurses, social workers, physical therapists, speech therapists, and providers from other medical disciplines. These professionals not only provide care to preterm infants, but can also help parents to get acquainted with the NICU

environment, to better understand their infants' medical status, and to make the transition to becoming independent caregivers at home. Throughout this process communication is pivotal. Several studies show that adequate communication between healthcare professionals and parents in the NICU contributes to parents' satisfaction with care and diminishes their stress levels [7–9]. More so, research shows that good communication ensures that parents feel more involved in the care of their child and, reversely, that poor communication can lead them to withdraw from the NICU and its staff, thereby hampering parent-infant attachment [10–12]. As such, it is important to understand what it entails for providers to *adequately* support parents during admission of their preterm infant to the NICU by means of interpersonal communication.

Over the past decades, the Family Integrated Care (FiCare) model has received increasing attention in neonatal care [13–15]. FiCare starts from the assumption that, ideally, parents and providers should work together in an equal partnership to foster parent-infant closeness, increase parents' participation in care, and ultimately improve short and long-term outcomes for preterm infants and their parents [16–18]. FiCare consists of four core pillars: (1) the *NICU environment*, promoting a shift from open-bay wards to single family rooms to enhance parents' feeling of safety and privacy and increase parent-nurse collaboration [19,20]; (2) *psychosocial support*, improving parents' coping and allowing them to engage with their infant [7,18]; (3) *staff education and support*, encouraging training of NICU staff on how to help parents become more involved in practical care activities (e.g., feeding, diaper changes, skin-to-skin care) [13,17,21]; and (4) *parent education*, offering training to parents to allow them to independently care for

Table 1
Levels of neonatal care.

Level of care	Description
Level 1 <i>Well-born nursery</i>	Postnatal care to stable term newborn infants as well as to infants born 35–37 weeks' gestation who remain physiologically stable. Stabilize infants' who are ill or born at < 35 weeks' gestation until transfer to a higher level of care
Level 2 <i>Special care nursery</i>	Medium to high complex neonatal care Level I capabilities plus postnatal care for infants born ≥ 32 weeks' gestation and weighing ≥ 1500 g who have physiologic immaturity or who are moderately ill with problems that are expected to resolve rapidly and are not anticipated to need subspecialty services on an urgent basis. Step-down unit from Level III. Stabilize infants born < 32 weeks' gestation or weighing < 1500 g until transfer to a higher level of care. Brief mechanical ventilation possible.
Level 3 <i>NICU</i>	Level II capabilities plus provision of sustained life support and comprehensive care for infants born critically ill, before < 32 weeks' gestation, or weighing < 1500 g. Access to pediatric medical subspecialists, advanced imaging techniques, and different forms of respiratory support.
Level 4 <i>Regional NICU</i>	Highly specialized neonatal intensive care Level III capabilities plus capabilities to provide surgical repair of complex congenital or acquired conditions and access to full range of pediatric medical (surgical) subspecialists and pediatric anesthesiologists onsite.

Based on the American Academy of Pediatrics [5].

their infant upon discharge [15,22]. Across the four pillars of FiCare, parent-provider interaction plays a significant role. Yet, to date, a systematic overview of the precise role and functions of communication within family integrated care is lacking. Moreover, it is unclear what ‘good’ parent-provider communication precisely entails.

In this review, we therefore systematically explore, synthesize, and analyze the literature on parent-provider communication in the NICU (level 2–4). Thereby, we focus specifically on medium to intensive neonatal care, excluding studies conducted in the well-born nursery (level 1). In this study we aim to: (1) assess the *main functions* of parent-provider communication in the NICU and (2) determine what *adequate* interpersonal communication in NICU settings encompasses, according to parents as well as providers. Defining interpersonal health communication as the (direct, non-mediated) verbal and non-verbal interaction between providers and patients, we use the Framework for Patient-Centered Communication by Epstein and Street as our starting point [23,24]. This framework has been developed to explore the relationships between different aspects of interpersonal communication and outcomes in oncology settings, yet fits well with the family-integrated approach to communication in neonatal care. As such, we seek to contribute to theoretical conceptualizations of NICU communication and – ultimately – to improve the quality of parent-provider interaction in practice.

2. Methods

This systematic review and meta-synthesis of qualitative research is part of a larger endeavor to systematically search and analyze the literature on the *functions* of (adequate) parent-provider communication and its *effects* on parent-related outcomes during NICU admission. The present study includes only qualitative studies, as it seeks to synthesize parents’ and providers’ told perspectives (‘narratives’) on the functions of NICU communication. The search strategies for the overall project as well as both quantitative and qualitative findings pertaining to communication *effects* are reported elsewhere [25]. This review is reported in accordance with the PRISMA statement [26]. The review protocol is registered with PROSPERO (CRD42020150218).

2.1. Data collection

The literature search for the overall project was conducted in October–November 2019 by a medical information specialist (JK) and included indexed terms and free-text words for ‘neonatal intensive care unit’, ‘parents’, ‘participation’, and ‘communication’ or ‘decision making’. The following databases were searched: PubMed, Ebsco/PsycINFO (23 October), Wiley/Cochrane Library

(24 October), Ebsco/CINAHL, Clarivate Analytics/Web of Science Core Collection, and Elsevier/Scopus (28 November). No restrictions on language or publication date were imposed.

The initial search yielded 5586 records, from which 2683 duplicates were removed. The remaining 2903 records were uploaded in Rayyan QCRI [27]. Title/abstract screening was conducted by two independent coders (NV, NL), representing the medical and parent-communication perspective. All conflicts were resolved through discussion involving a third coder (AvK). Because inter-rater reliability for abstract/title analysis was fair to moderate (Cohen’s kappa: 0.40) – likely due to the ‘fuzziness’ of the concept ‘communication’ – in case of doubt, records were included for full-text analysis. This resulted in 240 records for full-text assessment. Full-texts were retrieved via the library services of VU Amsterdam and OLVG Amsterdam.

Full-texts were assessed by WW and NL, applying the following inclusion/exclusion criteria: records had to be published in English and report on original, empirical, qualitative research focused on relevant stakeholders’ perspectives on parent-provider communication in the NICU. Unpublished (e.g. abstracts, theses, posters), non-empirical (e.g. research protocols, reviews, editorials, opinion pieces), quantitative, and non-English records were excluded. Also, records reporting on interprofessional communication or parent-provider communication prior to or following admission to the NICU were excluded. Records concerning the development of communication resources such as decision-aids, websites, or parent education, as well as studies on cultural or linguistic barriers between parents and providers and the importance of interpreters were excluded, due to our focus on direct, rather than mediated, forms of interpersonal communication. Inclusion and exclusion criteria can be found in Table 2. For an overview of the search see Fig. 1.

2.2. Data extraction and analysis

To systematically extract and organize data from full-text records, a data extraction sheet was used (available upon request). The sheet included meta-data (e.g., authors, publication year) and methodological aspects (e.g., study setting, sample, NICU level, analytic methods). Data on communication functions were extracted and analyzed by WW and NL applying the procedures described by Finfgeld-Connet [28]. Data was extracted from the results sections only. Findings reported in discussion sections were excluded, to avoid extracting interpretations rather than data. Direct quotes from interviews or focus groups were not extracted to avoid bias. Data were analyzed using combined deductive and inductive thematic analysis [29]. Relevant findings from included records were deductively categorized in the extraction sheet, according to the communication functions described by Street

Table 2
Inclusion and exclusion criteria for title/abstract screening and full-text analysis.

	Inclusion criteria	Exclusion criteria
Type of participants	Parents of admitted infants to the NICU (level 2–4), neonatal physicians, neonatal nurses, and other stakeholders involved in parent-provider communication.	Parents and neonatal health professionals in a level 1 NICU, and before or after a level 2–4 NICU admittance.
Phenomena of interest	Interpersonal neonatal parent-provider communication	Interprofessional health professional communication; parent-provider communication prior to or following admission to the NICU; development of communication resources; and cultural or linguistic barriers between parents and providers.
Context	NICU admission	Outside NICU admission
Type of studies	Published records, original empirical research, qualitative records	Unpublished records (e.g. abstracts, theses, posters), non-empirical studies (e.g. research protocols, reviews, editorials, opinion pieces), and quantitative records.
Language	English records	Non-English records

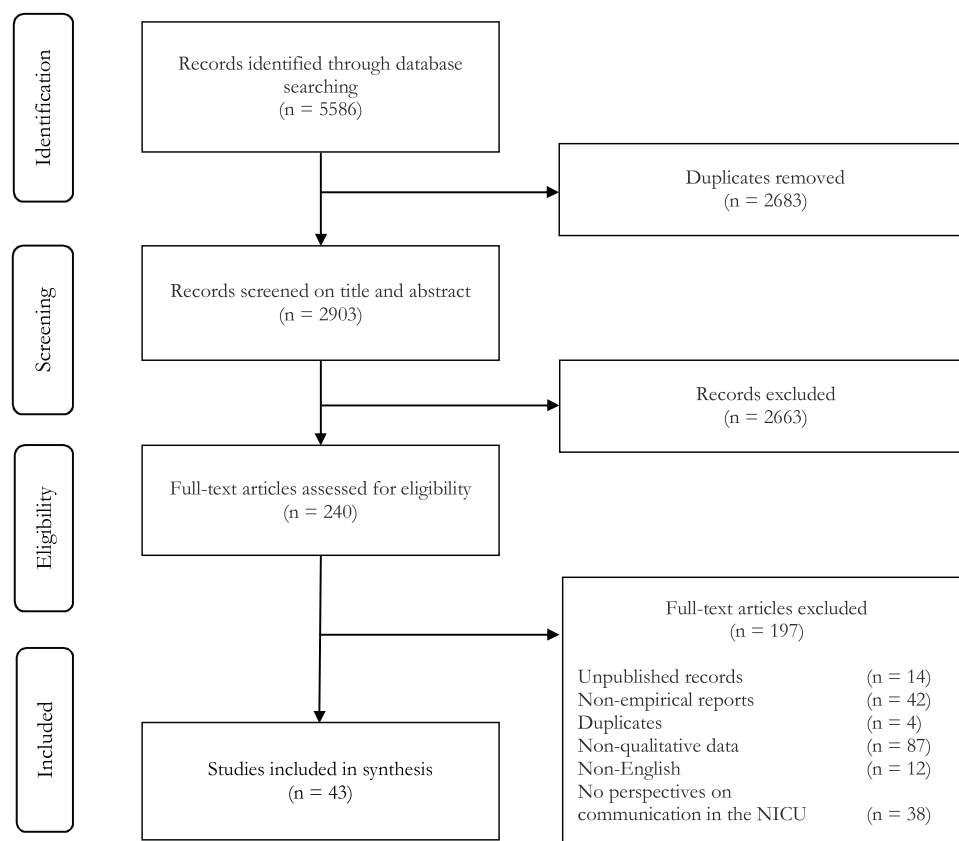


Fig. 1. Flow diagram of systematic review.

et al.: fostering relationships (building trust and report between providers-patients), information exchange (allowing providers and patients to share knowledge and insights), responding to emotions (helping patients cope with difficult circumstances), managing uncertainty (helping patients interpret uncertain medical scenarios), decision-making (making appropriate decisions), and enabling self-management (helping patients independently manage health-related problems) [23,24]. Inductive analysis allowed for new functions of NICU communication to emerge.

Subsequently, the data within each communication function was coded inductively by WW, focusing on aspects defining what constitutes ‘adequate communication’ according to relevant stakeholders. NL independently coded a subset of data (60%). Codes were discussed and a codebook was developed. Finally, remaining codes were categorized by WW and NL into themes within and across communication functions. Themes were discussed within the research team.

2.3. Quality assessment

The quality of each individual article was evaluated by two independent coders for, within the scope of the broader project, using the 16-item Quality Assessment Tool for Studies with Diverse Designs [30]. Detailed results are reported elsewhere [25]. In this study, no records were excluded based on the quality assessment.

2.4. Ethical considerations

The present study is part of IMPACT, a comprehensive research program on NICU Communication. This program was approved by

the Science and Ethics Committee of the Vrije Universiteit Amsterdam (VCWE-2019–132). The Medical Ethical Committee of the Amsterdam UMC, location VUmc judged that IMPACT is not subject to the Medical Research Involving Human Subjects Act, thereby waiving the requirement for medical ethical approval (2019.596).

3. Results

3.1. Study overview

The search yielded 43 studies reporting on functions of parent-provider communication in NICUs (N = 61) worldwide. Findings represent the perspectives of N = 965 parents, N = 54 family members, and N = 409 care professionals. Notably, three times as many mothers (N = 689) were included compared to fathers

Table 3
Study population.

	N
Parents	965
Mothers	689
Fathers	226
Not specified	50
Family members	53
Health professionals	409
Nurses	297
Neonatologists	112
Staff educators	11
Speech therapists	1

Table 4
Study characteristics of included records.

Authors, year	Purpose or aim	Geographic location	N, NICU (s)	NICU level	Sample	Methods
Able-Boone, Dockecki, & Smith, 1989	Investigated parents' and healthcare providers perspectives of their communicative interactions when a seriously ill infant is treated in an intensive care nursery.	USA	1	2 - 3	16 mothers 11 fathers 15 nurses 15 neonatologists	Open-ended and focused interviewing using an ethnographic interview method, data coding and analysis
Arockiasamy, Holsti, & Albersheim, 2008	Understanding the experiences of fathers of very ill neonates in the NICU.	Canada	1	3	16 fathers	Semi-structured interview, thematic analysis
Axelin, Outinen, Lainema, Lehtonen, & Franck, 2018	Explored the dynamics of neonatologist parent communication and decision- making during medical rounds in a level three neonatal intensive care unit.	Finland	1	3	15 mothers 7 fathers 2 neonatologists	Ethnographic approach with semi-structured interviews, thematic analysis
Aydon, Hauck, Murdoch, Siu, & Sharp, 2018	Explore the experiences of parents with babies born between 28–32 weeks' gestation during transition through the neonatal intensive care unit and discharge to home.	Australia	1	3	20 mothers 20 fathers	Semi-structured interview, thematic analysis
Baughcum et al., 2017	Examined the EOL experience of families in the NICU, and methodological issues, particularly the lack of standardized measures, have limited our understanding of how to optimize care.	USA	1	4	42 mothers 28 fathers	Semi-structured interview, thematic analysis
Berman et al., 2019	To explore the parent perspective on discharge home from the neonatal intensive care unit (NICU).	USA	N/A	2 - 3	14 mothers 1 father	Ethnographic approach with semi-structured interviews, thematic analysis
Bracht, O'Leary, Lee, & O'Brien, 2013	To develop, implement, and evaluate a parent education and support program that enhances family-integrated care in a Canadian neonatal intensive care unit (NICU).	Canada	1	3	39 mothers 11 staff educators	Evaluating structured interview
Brinchmann, Førde, & Nortvedt, 2002	To generate knowledge about parents' participation in life-and- death decisions concerning their very premature and/or critically ill infants in hospital neonatal units. The question is: what are parents' attitudes towards their involvement in such decision making?	Norway	N/A	N/A	19 mothers 16 fathers	Semi-structured interview, thematic analysis
Broom et al., 2017	To first describe parents' and staff perceptions of the benefits of each component of the FiCare program and second to explore parents' and staff perceptions of the FiCare program in an Australian NICU.	Australia	1	3	4 mothers 1 grandparent 8 nurses	Focus groups, thematic analysis
Bruns & McCollum, 1999	What roles do mothers assume in communication with NICU medical professionals participating in their infants' care?	USA	1	3	7 mothers 1 nurse	Semi-structured interview, thematic analysis
Bruns & McCollum, 2002	Examine the perspectives of mothers, nurses, and neonatologists on the importance and implementation of NICU practices related to caregiving, information exchange, and relationships within the context of family-centered care.	USA	6	3	55 mothers 122 nurses 18 neonatologists	questionnaires with open-ended questions, thematic analysis
Cox & Bialoskurski, 2001)	(1) Identification of factors associated with the provision of information that may facilitate and hinder family attachment. (2) Exploration of problems associated with communication caused by family and, in particular, mother–infant separation, while the infant is being cared for in a NICU.	UK	1	3	32 mothers 10 family members	Unstructured interviews and focus groups, thematic analysis
Falck, Moorthy, & Hussey-Gardner, 2016	Examine provision of Palliative Care as experienced by mothers and healthcare providers (HCPs) of NICU patients with life-threatening illnesses.	USA	1	4	6 mothers 5 nurses 1 neonatologist	Semi-structured interview, thematic analysis
Fenwick, Barclay, & Schmied, 2000	To improve care provided to parents of infants in the neonatal nursery by understanding and explaining the experience of mothering in level II nurseries.	Australia	2	2 - 3	31 families	Unstructured interviews, thematic analysis
Fenwick, Barclay, & Schmied, 2001	Explores the use of 'chat' or 'social talk' as an important clinical tool that can assist nurses achieve family-centred care in neonatal nurseries.	Australia	2	2 - 3	28 mothers 20 nurses	Semi-structured interview, thematic analysis
Flynn & McCollum, 1993	To obtain parents' opinions about the types and sources of formal support available for their family during their child's hospitalization, as well as the perceived adequacy of formal support and gaps in services.	USA	1	3	6 mothers	Open-ended focused interview, thematic analysis
Geetanjali, Manju, Paul, Manju, & Srinivas, 2012	To determine and assess the loss and grief response, and perceived needs of parents who are having their newborns in neonatal care units.	India	2	3	16 parents	Semi-structured interview, thematic analysis
Guillaume et al., 2013	to explore parents' perception of these first interactions and to identify the actions of caregivers that help or hinder its development.	France	3	3	30 mothers 30 fathers	Semi-structured interview, thematic analysis

Table 4 (Continued)

Authors, year	Purpose or aim	Geographic location	N, NICU (s)	NICU level	Sample	Methods
Harvey, Nongena, Gonzalez-Cinca, Edwards, & Redshaw, 2013	To explore parental information and communication needs during their baby's care in the neonatal unit with a focus on brain imaging and neurological prognosis.	UK	1	3	13 mothers 5 fathers	Semi-structured interview, thematic analysis
Hendriks & Abraham, 2017	To explore parental attitudes and values in the end-of-life decision-making process of extremely preterm infants (gestational age < 28 weeks).	Switzerland	1	3	12 mothers 8 fathers	Semi-structured interview, thematic analysis
Hinton, Locock, Long, & Knight, 2018	To understand the experiences of parents of infants who required surgery early in life. To identify messages and training needs for the extended clinical teams caring for these families—including pediatric surgeons, neonatologists, nurses, obstetricians, midwives and sonographers.	UK	1	3 - 4	33 mothers 11 fathers	Semi-structured interview, thematic analysis
Ichijima, Kirk, & Hornblow, 2011	Examines sources of parental stress in the two neonatal intensive care units (NICUs) located in New Zealand and Japan and explores how cultural norms of NICU care environments influence parental stress-related experiences and nursing support.	New Zealand / Japan	2	2 - 3	30 mothers 17 fathers	Quantitative questionnaire, thematic analysis
Jones, Taylor, Watson, Fenwick, & Dordic, 2015	To describe parents' and nurses' perceptions of communicating with each other in the context of the special care nursery.	Australia	2	2 - 3	27 mothers 4 fathers 12 nurses	Semi-structured interview, thematic analysis
Kavanaugh, Moro, & Savage, 2010	To describe nurse behaviors that assisted parents to make life-support decisions for an extremely premature infant before and after the infant's birth.	USA	3	3	40 mothers 14 fathers 29 nurses 42 neonatologists	Semi-structured interview, thematic analysis
Kavanaugh, Savage, Kilpatrick, Kimura, & Hersherberger, 2005	To describe decision making and the decision support needs of parents, physicians, and nurses regarding life support decisions made over time prenatally and postnatally for extremely premature infants.	US	2	3	6 mothers 2 fathers 2 nurses 6 neonatologists	Semi-structured interview, thematic analysis
Kodjebacheva et al., 2017	Investigated strategies for effective health communication in the NICU.	USA	1	3	6 mothers 2 fathers 17 nurses 3 neonatologists	semi-structured interview and focus groups, thematic analysis
Lemmen, Fristedt, & Lundqvist, 2013	To describe parents' experience of information and communication mediated by staff nurses before and during KC at neonatal wards.	Sweden	3	3 - 4	12 families	Semi-structured interview, modified content analysis on the basis of Graneheim and Lundman
Lemmon, Donohue, Parkinson, Northington, & Boss, 2016	To characterize the parental experience of communicating with clinicians about TH and neonatal encephalopathy.	USA	1	4	20 parents	Semi-structured interview, thematic analysis
Modé, Mard, Nyqvist, & Blomqvist, 2014	To explore fathers' perception of information received during their infants' care at a neonatal intensive care unit (NICU).	Sweden	2	3	8 fathers	Semi-structured interview, thematic analysis
Lundqvist, Nilstun, & Dykes, 2002	To examine and illuminate mothers' experiences and perceptions of the care given to them at neonatal clinics while facing the threat and the reality of losing their baby.	Sweden	1	2 - 3	16 mothers	Semi-structured interview, hermeneutic phenomenological method
Lupton & Fenwick, 2001	To investigate the ways in which women with hospitalized newborn infants construct and practice motherhood.	Australia	2	2 - 3	31 mothers 20 nurses	Semi-structured interview, thematic analysis
Lyndon, Wisner, Holschuh, Fagan, & Franck, 2017	To describe parents' perspectives and likelihood of speaking up about safety concerns in the NICU and identify barriers and facilitators to parents speaking up.	USA	1	3	14 parents	Semi-structured interviews, thematic analysis
Mburu, Wardle, Joolay, & Densmore, 2018	To discuss how technology design processes with and for mothers of preterm infants who are susceptible to stress look like in practice.	Namibia	1	3	15 mothers 10 nurses 5 neonatologists	Semi-structured interviews, thematic analysis
Payot, Gendron, Lefebvre, & Doucet, 2007	To explore empirically how parents and neonatologists engage in the decision to resuscitate a baby at the threshold of viability.	Canada	1	3 - 4	8 mothers 4 neonatologists	Semi-structured interviews, thematic analysis
Petty, Jarvis, & Thomas, 2019;	Focuses on what students and staff can learn from parents about what they feel is important to make their experience better.	UK	N/A	3	19 mothers 4 fathers	Narrative interviews, thematic analysis
Phuma-Ngaiyaye & Welcome Kalembo, 2016	To investigate the strategies for supporting maternal–newborn bonding for mothers whose neonates were admitted to an intensive care unit at a tertiary hospital in Malawi.	Malawi	1	3	10 mothers 5 nurses	Semi-structured interviews, thematic analysis
Raffray, Semenik, Osorio Galeano, & Ochoa Marin, 2014	To explore Colombian health care provider perceptions of barriers and facilitators to preparing families with premature infants for discharge home from the neonatal intensive care unit (NICU).	Colombia	1	2 - 3	11 nurses 3 neonatologists 1 speech therapist	Semi-structured interviews, thematic analysis
Rodrigues, Uema, Rissi, Felipin, & Higarashi, 2019	To understand the nursing team's perception regarding family centered care and its practice in the neonatal intensive care unit.	Brazil	1	3	19 nurses	Semi-structured interview, thematic analysis

Table 4 (Continued)

Authors, year	Purpose or aim	Geographic location	N, NICU (s)	NICU level	Sample	Methods
Russell et al., 2014	Explores parents' views and experiences of the care for their very premature baby on NICU.	UK	3	3	32 mothers 7 fathers	Semi-structured interview, thematic analysis
Silva & Osswald, 2010	Sheds light on the views of health care providers and parents, and its results can inform and improve the decision-making process in these settings.	Portugal	N/A	N/A	14 mothers 1 nurses 13 neonatologists	Semi-structured interview, thematic analysis
Uhl, Fisher, Docherty, & Brandon, 2013	To describe parents' care experiences during hospitalization of their children to identify strategies that could improve the provision of patient and family-centered care (PFCC).	USA	1	3 - 4	7 mothers 2 fathers	Semi-structured focus group & survey, thematic analysis
Weis, Zoffmann, & Egerod, 2015	To explore how parents of premature infants experience guided family-centered care (GFCC), and (b) to compare how parents receiving GFCC versus standard care (SC) describe nurse-parent communication in the neonatal intensive care unit.	Denmark	1	3	12 mothers 10 fathers	Semi-structured interview, thematic analysis
Weiss, Barg, Cook, Black, & Joffe, 2016)	To explore how characteristics of medical decisions influence parents' preferences for control over decisions for their seriously ill infants.	USA	2	3	25 mothers 5 fathers	Semi-structured interview, thematic analysis

(N = 226). The same applied to the number of nurses (N = 279) versus doctors (neonatologists, pediatricians, fellows, residents) (N = 112). Included studies used unstructured or semi-structured interviews, focus groups, and open-ended questionnaires to collect data and all applied thematic analysis. Table 3 summarizes the overall study population. Table 4 provides an overview of all included studies.

3.2. NICU Communication Framework

Seeking to determine the main *functions* of parent-provider communication in the NICU, based on our synthesis of data we developed a new model, constituting an adaptation of Street's framework [23,24]. The NICU Communication Framework encompasses four main functions of communication in the NICU: (1) building and maintaining relationships, (2) exchanging information, (3) (sharing) decision-making between parents and providers, and (4) enabling parent self-management.

The NICU Communication Framework befits the unique context of neonatal care, in which providers communicate with parents rather than with patients, and medical care is often both acute and long-term. The four functions of the NICU Communication Framework contribute to Family Integrated Care in the NICU, as communicative interaction is considered to be ideally directed towards fostering parents' participation in infant care in an equal partnership with providers, to achieve the best possible outcomes of care – both during admission and following discharge. Notably, in the NICU Communication Framework the function *building and maintaining relationships* also encompasses providers responding to parents' emotions and managing uncertainty. As relationships between healthcare professionals and parents in the NICU appear to be built and maintained first and foremost through regulation of parents' emotions and distress and uncertainty management (e.g. about infants' prognosis), these functions from the original framework are clustered.

In the NICU Communication Framework, communication functions are ordered sequentially. Building supportive relationships between parents and providers is considered fundamental in order to effectively exchange information about infants' medical situation. This, in turn, allows parents to engage in decision-making about treatment and care plans in their preferred role, which finally is seen as a prerequisite to empower parents to take part in practical care activities and feel prepared to independently care for their child upon discharge. The NICU Communication Framework, thus, offers an ideal model which outlines the ordered functions communication may have in parent-provider interaction. Needless to say, practice

may deviate from the theoretical ideal and in reality, functions may be achieved continuously, simultaneously, and sometimes in a different order.

Inductive analyses revealed five reoccurring factors that are important for *adequate* communication in NICU settings, across all functions of communication. These factors include providers' deliberate attention in their communication with parents to the (1) topic, (2) aims, (3) location, (4) route, and (5) design of the interaction. Prior to initiating interaction with parents, to ensure communication adequacy, providers should carefully consider the precise *topic*, or content, of what is going to be discussed (e.g. infant status, daily 'chit-chat', treatment information). Providers should determine the main *aim* of the conversation (e.g. informing, reassuring, or preparing parents). Furthermore, providers should think of the right *location* and timing of the communication (e.g., open ward or in a separate room, directly following admission or before discharge) and what is the proper *route* for communication. The route may include a choice between a (dedicated) nurse or a neonatologist, but also the option to offer written information or to conduct conversations via telephone. Finally, in the *design* providers should consider the communication style they want to use (e.g. objective and direct, empathic, coaching). Obviously, in considering these factors providers should take into account parents' preferences and allow room for their contributions, too. Together, the five factors of adequate communication form the acronym TAILORED, which can serve as a mnemonic for providers to memorize what it entails to adapt their communication to parents' situational and personal needs. The four communication functions and five factors of adequate communication, jointly constitute the baseline for the NICU Communication Framework (Fig. 2). What it entails to adequately address each of the aforementioned factors across the four functions of communication, will be discussed next.

3.3. Functions and factors contributing to adequate NICU communication

3.3.1. Building and maintaining relationships

Building and maintaining positive relationships with parents includes responding to their emotions, fulfilling their supportive needs, and helping parents to manage uncertainties in their infant's care. Properly attending to this function of communication highly impacts parents' satisfaction with infants' care [31,32]. Analyses reveal that to build solid parent-provider relationships, parents want to discuss medical *topics* with their infants' neonatologists on a

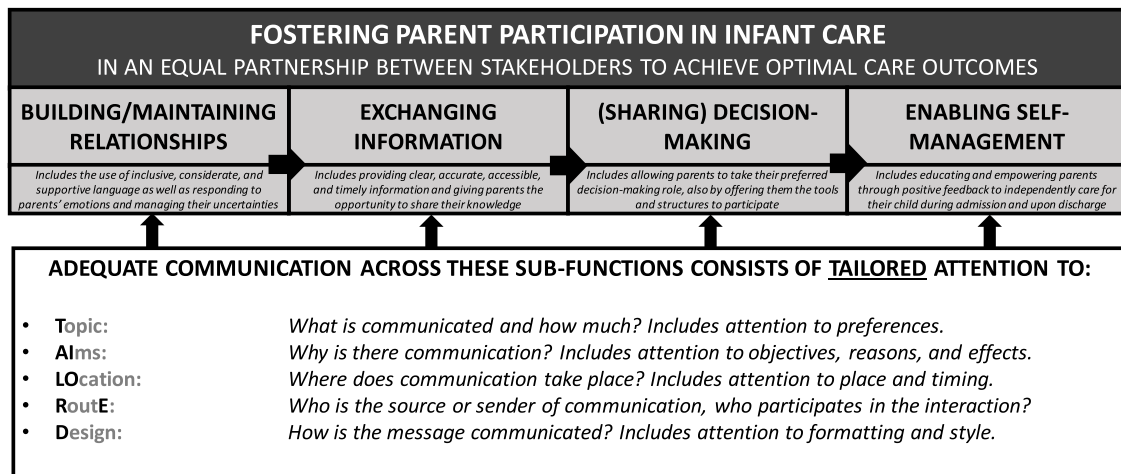


Fig. 2. NICU Communication Framework.

regular basis. This helps them to become more familiar with the NICU environment, to feel reassured, and more at ease to ask questions [32–40]. To develop good relationships with nursing staff, parents also particularly appreciate daily ‘chit-chat’ on topics that do not necessarily concern the infant’s care:

“Nurses who ‘chatted’ and conveyed a sense of partnership and equality were also frequently mentioned as supportive. Parents valued nurses who [. . .] were able to engage in conversations that recognized that there was ‘life outside’ the nursery [34].”

In their endeavors to build relationships with parents, providers should aim to make parents feel comfortable in the NICU and feel more involved with their infant’s care. They should strive to get to know the parents and respond to their personal needs [33–35,37,39,41–47]. Parents want to develop good relationships with providers to receive guidance and support during difficult times, but also to ascertain their infant receives the best of care possible [42,44]. Parents appreciate reassurance from providers, as this helps them mitigate their fears and overcome traumatic experiences [34,36,39,48–52]. Having regular conversations in a secluded location such as a single room increases parents’ sense of privacy, their confidence to ask questions, and the idea that providers take the time to listen. This allows parents to show their emotions, in turn enabling providers to support parents during difficult conversations [53]. In terms of communication route, parents prefer to build and maintain trusting relationships with dedicated nurses and neonatologists, rather than encountering many different professionals [38,44,54]. Conversation designs that can be used by providers to build a good relationship include showing concern, understanding, and empathy to parents as well as demonstrating their professional experience [32,34,35,51,53,55,56]. Parents particularly appreciate communication that is respectful, compassionate, caring, and genuine to build and maintain good relationships with provider [53,57,58].

“Families reported that their relationships with staff were central to their satisfaction with care. They judged these relationships based on whether providers were physically available, compassionate, and genuine in their interactions. This was true across specialties, but parents most frequently acknowledged the care and dedication of nursing staff [32].”

3.3.2. Exchanging information

Exchanging information involves a continuous sharing of knowledge between parents and providers throughout infants’

admission. Parents and providers can exchange information on topics regarding the medical condition, treatment plans, and possible outcomes of the infant [31,36,45,48,50–53,55,59–62]. In order to allow for optimal information exchanges, providers should consistently aim to help parents understand why certain care is provided, what this entails, and which treatment options are available to enable parents to participate in their infants’ care [53,55,57,61]. Providers should explicitly encourage question-asking as well as information sharing. This increases parents’ feeling of involvement, helps them to engage in decision-making, and reduces their anxiety:

“Participants reported that the anxiety of mothers was relieved when the nurses constantly informed them about their newborn’s condition and treatment, such that the mothers understood the health status of their babies [48].”

Also here, parents prefer regular information exchanges in secluded locations to ensure that bad news, or unexpected or complex information is conveyed privately [31,32,36,45,48–53,55,59–62]. To ensure information provision is consistent, a designated nurse and neonatologist should be assigned throughout admission (route). Receiving conflicting information or different opinions from different providers may leave parents confused [38,40,43,45,57,59,63–65]. During and following information exchanges with neonatologists, nursing staff can assume a supporting role by helping parents understand the information provided [31,39,50,55,57,60,62,66]. Conversation designs that can be used by providers to ensure adequate information exchanges include being direct, consistent, clear, and thorough [32,39,42,45,57,58,62,67–69]. Furthermore, in providing information providers must avoid jargon and carefully consider the proper amount of information given, to reduce parents’ distress and dissatisfaction [32,34,35,39,49–53,57,60,61,70].

“The fathers perceived disagreement between staff members as upsetting and confusing. Conflicting information and conflicting opinions among the staff about, for example, limits for alarms from medical equipment, were perceived as very negative, and physicians’ use of medical terminology impeded the information flow [45].”

3.3.3. (Sharing) decision-making

Throughout hospitalization, parents and providers continuously have to make decisions about treatment. Depending on parents’ preferences as well as medical circumstances over the

course of admission, decisions are made by providers, parents, or jointly. Analyses show that, generally, parents prefer to be involved when medical expertise is not required, when the risks involved are high, or when they consider issues as ‘normal parenting’ decisions (topics) [67,69,71].

“Preferences for greater parental control were associated with high perceived risk, high parental knowledge about or personal experience with the decision, involvement of foreign bodily fluids such as blood, and similarity to decisions that parents perceived to be part of the normal parental role [71].”

When parents feel decisions require medical expertise, they prefer to delegate decision-making to providers. Nonetheless, they want to be informed about the decision-making process [68–72]. Thus, providers should aim to involve parents in their preferred decision-making role, as this gives parents a feeling of being taken seriously and provides them with a sense of control [31]. However, this aim is not always achieved:

“[Parents] wanted inclusion in conversations about their child’s care and engagement in decision making, but often struggled to find a way to be involved [54].”

Parents emphasize that also in order to engage in decision-making, a secluded location to talk to providers is necessary [50]. Access to decision-aids, such as pamphlets explaining conditions, assists parents in the decision-making process (route) [51,53,57,68]. In terms of communication design, providers must seek to adapt their communication style to parents’ personal needs concerning their involvement in decision-making [32,65,71].

“Being listened to in a genuine and consistent manner was also very important to many of the parents. They wanted to have a voice and be taken seriously when it came to identifying changes in their baby’s condition and decisions about care including strong beliefs some parents held about how early care impacts on future outcomes of their babies [67].”

3.3.4. Enabling parent self-management

Enabling parent self-management concerning their infants’ care is key during admission and after discharge. Providers can enable parent self-management by offering education on topics such as skin-to-skin care, breast-feeding, and changing diapers, or by teaching them about the use of medical equipment around the NICU [34,36,42,43,45,54,67]. Practical preparation for discharge is important, too [36,43,45,60,73]. More so, psychological care, through positive feedback, is deemed crucial:

“Nurses also verbalized the importance of making parents feel positive about their ability to provide direct care to their infant. There was a genuine desire to assist parents to ‘parent’ and to make sure they were left feeling positive about doing the activity again or ‘trying’ again. Two nurses discussed possible differences between mothers and fathers stating fathers often ‘required more encouragement’ than mothers to be involved in caring for their baby [34].”

Providers should aim to increase parents’ confidence and empower them to participate in their infant’s care during admission and to prepare them for discharge and their time home [36,44,45,54,73]. In terms of location, education may take place at infants’ bedside or in group sessions. However, timing is particularly important. Providers should ensure timely education and discharge planning, to avoid overwhelming parents with information too close prior to discharge and to maintain parents’ confidence in their parenting skills once at home [43,45,52,60,73]. In order to adequately self-manage infant care once providers become less available, parents need to have access to reliable information resources (route) [36,54,60]. These may include

parents’ notes from conversations with providers, but also supplementary written materials which can be explained by providers during discharge preparation [32,45,57,60,63]. When encouraging parents to participate in care, providers should carefully observe parents’ responses and explicitly encourage question-asking (design). This reduces the risk of misunderstanding and discouragement [36,44,45,52,54,60,62].

“When [parents] perceived that nurses were not fully engaged in ‘helping’ them with their parental role, they became disaffected and dissatisfied. Working in a ‘harmonious’ way with nurses was challenging for parents when they perceived nurses to be ‘controlling’ [34].”

4. Discussion and conclusion

4.1. Discussion

This systematic review and meta-synthesis provides a comprehensive overview of the role of interpersonal communication between parents and providers in NICU settings and offers practical insights into what it entails to communicate adequately within this context, according to both parents and healthcare professionals. This study has led to a first outline of the NICU Communication Framework, encompassing four functions of parent-provider communication: (1) Building and maintaining relationships, (2) exchanging information, (3) (sharing) decision-making, and (4) enabling parent self-management. The NICU Communication Framework provides a contextualization and refinement of Epstein and Street’s Framework for Patient-Centered Communication in oncology settings [23,24]. Our data showed that several functions included Epstein and Street’s Framework had to be merged and no new functions emerged in the ideal model. The new NICU Communication Framework fits within FiCare practices, which seek to foster parents’ participation in infant care in an equal partnership with providers, to achieve the best possible outcomes of care – both during admission and following discharge [13,18,47]. We therefore believe it is important that insights from the NICU Communication Framework are adopted and integrated in FiCare, to further improve parent involvement in infant care.

Notably, there is a sequential order between the different functions of communication in the NICU Communication framework, with the fulfillment of each function being fundamental for optimally achieving the next. Thereby, enabling parents to self-manage in their infants’ care, inherently builds on having good parent-provider relationships, adequate information exchange, and involving parents in decision-making in their preferred role. As such, neonatal providers can be seen to carry a double task of being responsible for infant care as well as for empowering mothers and fathers in their parental roles. This requires unique skills from NICU staff. Within FiCare, several educational programs have been developed to facilitate providers in striving to improve (health) outcomes of infants and parents through greater parent-participation [15,74,75]. We recommend such programs to incorporate a communication component.

In addition to the functions of NICU communication, our analyses also show what constitutes adequate, tailored communication between parents and providers. The importance of tailored communication and its potential cost-effectiveness in healthcare was already discussed two decades ago [76]. More recently, research showed that providing tailored communication results in better medical adherence, better health outcomes, and a higher quality of life after recovery [23,24,77–81]. However, what it exactly means to tailor communication to patients’ needs, is by no means evident from the literature. The present study shows that, within NICU settings, across all four functions of interpersonal communication, adequate interaction entails that providers seek

to consistently pay attention to the *topic, aims, location, route*, and *design* of their communication – thereby adapting their communication to parents' needs in a given situation. Providers may use the acronym TAILORED as a mnemonic to remember the five factors of adequate communication.

Interestingly, while the ways in which the five factors take shape differ for each of the communication functions, the results consistently show that across all functions parents need providers to ensure that interaction takes place in private settings – enclosed locations where parents have more privacy, feel at ease to ask questions, and where they can participate in discussions and in care. This result resonates with findings of van Veenendaal et al., who demonstrate that single family rooms contribute to parent participation during NICU admission [82]. This implies that for optimal communication to take place, NICUs should consider implementing single family rooms rather than open wards. Taken together, these insights are beneficial for understanding what is needed to facilitate tailored and family-integrated parent-provider communication in neonatal care [83].

It may seem contradictory that, while the NICU Communication Framework promotes an equal partnership between parents and providers, it only formulates specific requirements (i.e. TAILORED-factors) for providers on how to communicate with parents. After all, a true partnership would entail that parents contribute equally to the interaction and, consequently, that requirements should be formulated for them, too. However, while parents' role in family-integrated care is equally important to the roles of healthcare providers, their role is also unique. Given the emotionally challenging circumstances for parents imposed by the NICU, we believe it is important that providers take the lead using the TAILORED-factors in order to conjure an equal partnership and individualized communication with parents throughout their presence in the NICU.

Notably, there is a great asymmetry with regard to the participants included within the data of this meta-synthesis. Fathers are heavily underrepresented in the data. However, studies have shown that fathers experience also high levels of stress, respond differently to situations in the NICU compared to mothers, and use different coping mechanisms throughout admission [84,85]. It is thus important to further explore fathers' perspectives to provide adequate support during this difficult period and after [86]. The same asymmetry exists between providers. Nurses' perspectives are overrepresented compared to neonatologists. The role of nurses as primary informants for parents is increasing [87]. The overrepresentation of nursing staff may also be a reflection of the size of the nursing team compared to the number of doctors in a neonatal ward. However, as the results show, certain communication functions are primarily fulfilled by physicians and parents require adequate interaction from both types of providers. As such, more attention should be paid to neonatologists' role in parent-provider interaction.

The results of this meta-synthesis have to be interpreted in light of some limitations. First, inclusion for full-text analysis was limited to English articles, resulting in the exclusion of 12 articles and inducing a bias towards Anglo-Saxon neonatal cultures. Although our analyses were comprehensive and thematic saturation was reached at all levels, we cannot be certain that excluded records would have revealed different insights concerning parents' and providers' preferences and needs for NICU communication in and between different cultures. Such information could help to overcoming communication barriers when cultural differences between parents and providers arise [88,89]. Second, we cannot ascertain whether participants and NICUs overlap between different studies, thereby potentially affecting our interpretations. Third, the use of Epstein and Street's Framework for Patient-Centered Communication may have biased our analyses towards finding similar communication functions for NICU interaction. Yet,

in addition to deductive analyses, we also conducted inductive thematic analyses to allow for new functions to arise – which was not the case. A strength of this study concerns the involvement of a multidisciplinary research team, including health communication researchers, neonatologists, experts of family-integrated care, parent representatives, and a medical information specialist. Independent analysis of all records and data by multiple coders enhances the validity of our findings. Finally, in our analyses, we purposefully included the views of parents as well as healthcare professionals, thereby warranting a full-blown picture of what adequate NICU communication entails.

4.2. Conclusion

While the past years have seen increasing attention to the communicative interaction between parents and providers in the NICU, to date – and to the best of our knowledge – no systematic review has been performed to aggregate all findings concerning the *functions* of parent-provider interaction and the characteristics of *adequate* NICU communication. This review sought to include the perspectives of both parents and providers and, through a meta-synthesis, develop a new theoretical framework for family-centered and tailored communication in neonatal care. The resulting NICU Communication Framework is uniquely applicable to the neonatal context and can support further refinement and implementation of the Family Integrated Care Model. The present results and framework can be used in health communication research that seeks to improve parent-provider interactions in the NICU. Upon empirical testing, the NICU Communication Framework can be used to develop effective interventions to enhance tailored communication between parents and providers during their presence in the NICU – ultimately resulting in greater parent participation and better health outcomes. Also, the *effects* of communication on parent-related outcomes should be carefully explored in order to build a more comprehensive framework [25].

4.3. Practice implications

The findings have direct practical relevance, as providers may use the framework and the TAILORED acronym – which serves as a mnemonic – to refine their own communication strategies when engaging in dialogues with parents. TAILORED includes all factors for providers that play an important role in fulfilling the different functions of parent-provider communication in a given situation. Upon further testing of the NICU Communication Framework, NICUs may adopt this acronym to positively impact their staff's communication strategies. For instance, the acronym and short explanations of the different factors may be printed on a pocket-sized card to serve as a tangible reminder prior to engaging in conversations with parents. Also, staff training sessions based on the NICU Communication Framework may be useful to improve practice. Whilst the framework is thus still under development, it has the potential to significantly affect both research and practice.

Informed consent

All personal identifiers have been removed or disguised so participants and patients described are not identifiable and cannot be identified through the details of the story.

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 core team member of a Dutch parent-support organization for parents of preterm infants (Veerkrachtige Ouders) provided feedback on the final version of the manuscript.

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CRediT authorship contribution statement

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

Declaration of Competing Interest

The authors report no declarations of interest.

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