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## **Communication, information, and the parent–caregiver relationship in neonatal intensive care units: a review of the literature**

Short title: Neonatology and caregiver–parent communication in NICUs

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### **Abstract**

This literature review focuses on the neonatal context. It provides an update of knowledge on the psychosocial consequences and communication needs expressed by parents. It highlights the obstacles to communication and proposes lines of thought for the development of new training systems to improve the communication practices of caregivers.

**Objective:** This review aims to assess and categorize the specific needs and expectations of families in terms of communication within the neonatal intensive care unit (NICU).

**Methods:** A bibliographic search was carried out on the Web of Sciences, PubMed and PsycArticles databases with the following keywords: “neonat\* AND new\* AND communication AND parent\*”.

**Results:** In total, 16 papers were selected showing that information and communication are particular needs for parents in NICUs. They are confronted with a stressful situation and have to deal with the fear and anticipation of the situation in a context of uncertainty. Parents are satisfied with the caregiver–parent relationship when the type of communication is adapted to the context and to their changing needs. Conversely, they feel excluded when they cannot be involved as they would like to be in the care or in the decision-making process.

**Conclusion:** The development of new communication training methods and tools such as simulation would allow healthcare workers to acquire new communication skills focused on the needs of families.

**Keywords:** communication; communication needs; parents; neonatal intensive care; access to information; family-centered care.

## **1. Introduction**

In France, every year, one child out of 35 is born in a situation of vital distress and has to be hospitalized in a neonatal intensive care unit (NICU) [1, 2]. In this context, parents must face difficult situations on a daily basis. They find themselves immersed in the unknown in a complex care environment, confronted with fear, uncertainty, noise, and constant commotion [2, 3]. In this hyper-technical and “alarming” area, combined with the anxiety and confusion about their child’s health, parents must make informed decisions, often in a hurry, in the name of what is “best” for their child [4]. These decisions, which often generate ethical thinking [5], have a significant impact on the parents’ emotional state, their idealized representation of parenthood, the balance of the family, and also the child’s future [6].

Given these difficult conditions, parents have a particular need for information and communication in order to cope with fear and anticipation of the situation in a context of uncertainty and stress where risk is omnipresent [7–9]. Early involvement of parents in decision-making processes and individualized support would limit the risk of posttraumatic stress and severe depression in the mother in the event of the child’s death [10]. However, parents’ unrealistic optimistic expectations and emotions induced by these specific care situations may have an impact on their concentration, the processing of information shared by doctors [11], and their ability to make decisions [12]. There is also a relatively asymmetrical doctor–parent relationship where medical knowledge and experience predominate in the decision-making process [13]. Furthermore, several studies have highlighted a lack of control over the situation expressed by parents despite their willingness to be involved and participate in decisions concerning their children’s care [14–18]. This can be explained by the fact that the transmission of information from doctors to families is influenced by their perception of the latter’s desire for information [19]. Caregiver–family communication should be considered as a central element of medical care because of its contribution and effects on

shared decision-making, on the quality of the interpersonal relationship, on trust, and on the parental satisfaction with the quality of care [4, 12, 19]. This literature review, through a synthesis of the work on specific communication processes and issues in NICUs, aims to evaluate and categorize the specific needs and expectation of families regarding communication.

## **2. Method**

### ***2.1 Selection of items***

A systematic review of the literature was conducted to select review articles (first selection criterion) specific to the neonatal context (second selection criterion) that empirically studied relational dynamics and caregiver–family communication (third selection criterion) with an interest in parents’ and caregivers’ perceptions (fourth selection criterion). The successive steps involved in the selection of articles are presented in **Figure 1**. A Boolean bibliographic search was carried out on the Web of Sciences, PubMed, and PsycArticles databases with the following keywords: “neonat\* AND new\* AND communication AND parent\*”. Only English-language articles published up to July 2020 were included.

Articles whose material differed from that of a literature review were excluded, but the type of methodology used was not a criterion for exclusion. Articles that did not address communication processes in neonatal medical and intensive care units were also excluded, as were those whose study population did not include caregivers and parents.

The selection of articles was based on three successive reading stages: first, the exclusion criteria were used for reading the titles, the abstracts, and the content of the articles. Then, the articles were sorted according to their type of publication, design, methodology, and general study topic and were ranked according to their relevance value. Inter-rater agreement accompanied the entire article selection process.

### ***2.2 Analysis of articles***

The selected articles were read in their entirety to extract: (a) general descriptions (author names, year of publication, geographical context, general subject and objective of study); (b) methods used; (c) results highlighting families' needs and expectations regarding communication, caregivers' perceptions of needs, satisfaction and recommendations for improving communication practices. After data extraction, the analysis criteria were cross-tabulated to identify (a) how parents and caregivers perceive communication and information sharing in an NICU; (b) the different categories of needs in the caregiver–family relationship in an NICU; and (c) ways to improve communication practices.

### **3. Results**

#### ***3.1 General information***

The 16 reviews selected focus on the caregiver–family relationship either as a whole or according to a specific criterion, such as communication mode, illness trajectory, type of communication, or gender of the parent. Two studies had conducted a meta-analysis including one in 12 different countries. Three studies focused on decision-making processes. Seven studies looked at parents' experiences and communication need in the NICU. Five studies focused on barriers to and facilitators of the caregiver–family relationship. Four reviews focused on the technical and organizational devices, their feasibility, usefulness, and limitations in improving communication and meeting parents' needs. A summary of the design and subject matter of the studies is given in **Table 1**. Our synthesis work was organized along two lines: (a) relational needs experienced and expressed by parents in NICUs; (b) communication, information, and decision-making issues.

#### ***3.2 Needs of families in the caregiver–parent relationship***

Communicating and disseminating information about the evolution of the patient's health condition, as well as explaining the different care options and the functioning of the NICU,

can help reduce parents' fear of the unknown, their anxiety about the uncertainty of the situation, their feelings of exclusion, and their sense of powerlessness [20].

### *3.2.1 Need for security*

In a NICU, parents have a fundamental need to feel safe with their child. To reduce their stress and anxiety, parents are constantly seeking information to understand their child's state of health and to learn to spot signs of progress on their own [21, 22]. To reduce the uncertainty and fear significantly, it is important for parents to receive explanations about the functioning of the NICU and information about the indications and functioning of the different medical equipment needed to monitor and safeguard their child's vital functions [23-25]. In addition, mothers report being more vigilant when they do not have a trusting relationship with the neonatal nurses assigned to their child's care [26].

Regarding the perception of professionals, communication may be hampered by the inaccessibility of some nurses, a family's preference for a nurse, or parents' inability to ask for help [25]. Frequent changes in staffing and NICU occupancy rates contribute to parental anxiety. They feel insecure about the number of caregivers around their child and anticipate the risk of errors or mismanagement due to a potential lack of knowledge on the part of the caregivers regarding the trajectory of their infant's illness [24-27].

Anwar Siani et al. showed that the use of webcams allowed parents to feel safe even when they were away from their infants. Parental stress caused by uncertainty and anticipation is reduced by the perceived closeness and reassurance of the caregiver's presence [21]. For caregivers, videoconferencing facilitates meeting with the whole family. It enables a more complete assessment of the overall situation in the home and provides, in their opinion, additional security for the families [28]. Moreover, parents attribute a way of anticipating possible bad news to this type of device, via the possibility of analyzing the body language of the caregivers [21]. A majority of caregivers find teleconferencing devices and SMS useful

for communicating updates to parents of infants in NICUs [21, 22, 28]. However, it has been shown that use of webcams can cause emotional reactions in some parents due to the unpredictability of being confronted with a sudden deterioration in their child's health inherent to NICU settings [21].

Finally, for some parents, a feeling of insecurity may arise during periods of transition of care. Parents are apprehensive about transferring their child to a lower-technology service with fewer staff, despite the positive evolution of their child's health [25].

### *3.2.2 Need for legitimacy*

Parents need recognition of their parental role in both caregiving and decision-making [25, 29, 30]. Fathers tend to give priority to mothers but want their own skills and abilities to care for their child to be recognized and noticed by neonatal teams [25]. They express a tendency to be left on the periphery of care and regret that staff give priority to supporting mothers [25].

Proximity to their child is an essential factor in fulfilling their role as father. They consider any relationship that encourages partnership as a source of valuable support [25]. This closeness is only possible with the provision of information and a facilitating attitude from caregivers: A lack of information or conflicting information leads to confusion among fathers about physical contact with their child [30]. They also explain that their parenting role can be disrupted by their fear, apprehension about navigating around equipment, and difficulties in seeking and receiving approval to touch their infant [30].

Finally, some fathers express a feeling of exclusion induced by a lack of communication from the teams or by their perception that nursing care is reserved for mothers. This feeling of exclusion is all the more important with regard to comfort care when the child's state of health is considered critical [30].

### *3.2.3 Need for reassurance*



Stress and worry about the child's functional level are pervasive feelings for parents in the NICU, especially when they cannot be at the bedside [21, 22, 25, 27, 28, 31]. Monitoring their infant's progress and accessing health information are ways to reassure them [21, 23, 28]. There are mobile applications that record and provide information on milestones and aspects of infant care. The use of these devices has been shown to have a positive effect on parental anxiety [22]. A reduction in stress and anxiety has also been observed when using webcams in some NICUs. The ability to see their child at any time provides parents with a means of reassurance about their child's health and allows them to obtain a more "real" picture of the situation that is often more acceptable than the one they imagined [28]. Others, however, experience helplessness, sadness, guilt, or stress using the device when they are unable to visit their child [28].

With regard to interviews with doctors in the NICU, hope for the child's survival would help parents to cope with their anxiety, regardless of the severity of the situation [23]. However, studies have highlighted a desire on the part of parents to receive accurate and balanced information that does not convey false hopes about the outcomes or prognosis of the child [23,26,29]. In the case of extreme prematurity, it has been shown that parents' objectivity in making decisions about their children's care is not limited by the provision of negative statistical information with a hint of hope [27]. Indeed, parents expressed a need to receive all the necessary information related to their questions, whatever their emotional value, in order to be able to participate in the care and have the most accurate idea possible of the expected course for their child [27].

Concerning the experience of parenthood during hospitalization, parents express difficulties and apprehension at the beginning of their stay about caring for their child and their interaction with him/her. The implementation of a joint assessment with the nurses, the establishment of a relationship of trust and support with the staff, and personalized support in

acts of care enable them to feel reassured about their parenting skills and to approach the end of the hospitalization more calmly [31]. Some fathers report feeling a loss of control as a parent in the NICU when they feel they are receiving conflicting information about their infants or perceive an inconsistent change in care routines [25,30]. Parents also report that their needs for support and reassurance on admission to this unfamiliar environment are not fully addressed by NICU nurses [25].

#### *3.2.4 Need for support*

In the NICU, parents' emotions are at their peak and can sometimes be ambivalent and stress-dependent [23]. When isolation is added, parents seek even more support from professionals in the NICU [22]. They express a need to meet other parents in the same situation [22, 23]. Several studies have shown that parents seek support through social networks [22]. Social support, found within social networks, makes it easier for parents in difficulty to meet their most urgent needs, namely, managing their emotions, finding resources, and planning for their child's future [22]. The development of palliative programs (training of caregivers in support, provision of "family rooms," funeral support) contributes to the satisfaction of parents who have reported greater satisfaction with their support in the event of poor prognosis or the death of their child [29,32].

In addition, several studies show that specific support and the establishment of intervention and support groups focused on grief and bereavement reduce depressive symptoms and psychological distress in parents [32]. Parents report that it is important at such tragic times that nurses are available to listen and allow them to express their feelings. They also expressed appreciation for the compassion of the caregivers and open and honest discussions about their loss [23, 32]. Religious representatives were also found to be an important source of support for parents [22].

#### *3.2.5 Need to understand and prepare*

Parents explain that they need information and communication to address their feelings of shock, anticipation, and uncertainty [23]. In order to reduce their anxiety, it is recommended that they be prepared in advance for NICU practices and procedures as well as for service transfers [20]. Antenatal consultations with neonatologists reduce parental anxiety, increase understanding of care actions, promote a better parent–professional relationship, and improve understanding of the disease process [23]. Parents sometimes report difficulty in assimilating all the information, especially in a context of uncertainty. They appreciate having the necessary information repeated to them so that they can better understand their child’s situation [33].

Understanding the situation is enhanced by the continuous provision of information about the child’s progress, especially when it is perceived as empathetic and consistent [24]. In the event of death, a majority of mothers report being satisfied with the information provided postmortem. Their grieving process is facilitated by understanding the causes of death, by the support received, and by having a place to share experiences. In cases where parents judged postmortem communication negatively, they noted a lack of frank and honest information about their child’s situation [32].

### *3.2.6 Need for time*

Kharrat et al. have shown that it is important for parents to have time to understand and assimilate the information given during prenatal consultation in cases of risk of extreme prematurity [27]. Time is necessary to make decisions about the care plans to be implemented in the best possible conditions and in accordance with their values and beliefs as well as with the prognosis of their child [22,27]. Indeed, the child’s quality of life is a central factor in the decision-making of parents who want to ensure that they have made the best decision. To do this, parents express the need to know every detail and to take the time necessary to ensure

that all information is provided [27, 29]. In addition, they need more or less time to accept reality. [22].

### ***3.3 Communication, information sharing, and decision-making***

#### *3.3.1 Communication style*

A great variability in communication styles and interventions can be observed between institutions, cultures, and clinicians [34]. This variability can be explained by the uniqueness of each situation, especially in the field of extreme prematurity [34]. Parents value a communication style that facilitates collaboration by offering clear and detailed information, where information is presented in a compassionate way and where there is room for questions [27, 29, 34]. Parents also feel that a communication style based on reassurance facilitates their engagement in a trusting relationship. In this context, their interlocutor should be characterized as sensitive, compassionate, respectful, and attentive to their requests and needs [20, 26]. Furthermore, parents link an empathic communication style with the degree of perceived support, the quality of their relationship with professionals, and with their stress level [25, 34]. This relational harmony is characterized by the attribution of a role in collaborative care and decision-making, access to open conversations, and the provision of tailored and personalized advice [26, 27, 29]. Parents report receiving satisfactory emotional support when they feel that interactions between professionals are consistent and when their conversations express solidarity [26, 27, 29, 34].

Parents also feel satisfied when information is given in an open and honest way. They wish that information could also be given by neonatal nurses, whom they consider more accessible [25, 27]. Communication is considered engaging by parents when it anticipates their questions and concerns about the care and the future of their child [20, 23, 34].

At the same time, professionals find it difficult to adapt the types of communication according to the context and the parents. They say they favor a frame of reference based on the parents'

perceived personality, but the parents' stress and uncertainty about the care situation can bias their judgment [23].

### *3.3.2 Communication time*

Time for discussion between professionals and parents is recommended from the moment of admission. These early meetings should respond to the parents' need to be prepared and to be able to understand as well possible the process and procedures that will be adopted later on [23, 27]. They allow parents to be involved in the decision-making process as early as possible [31]. Parents have an increased need for regular contact with the nursing staff during their stays in the NICU [23]. During these exchanges, doctors focus on the critical aspect of the child, the uncertainty and insecurity of the prognosis; mothers seek information about their child's health status and technical information but also support and guidance for coping with this stressful situation [23].

During the NICU stay, parents report an increased need for information about their infant's health condition and apprehension that they will not be informed of important changes in their infant's health condition during their absence [24, 27]. Clinical visits seem to be an appropriate time for parents to receive the necessary information about any evolution in health status [23, 25]. Before discharge from the NICU, it is recommended that professionals schedule a specific consultation with parents to prepare them for the transition of care [31]. When the child's life is limited, early discussion and the introduction of the concept of care limitation can provide parents with the necessary time to prepare for the inevitable [29]. Indeed, parents may consider discussions about organ donation or requests for autopsy to be inappropriate or ill-timed [33].

### *3.3.3 Communication mode*

In their study of the parent–nurse partnership, Brødsgaard et al. link barriers to knowledge sharing to staff communication skills, nurse/parent collaboration and the types of information

discussed. Although the information shared may meet parents' emotional needs, they may not receive adequate information about their children's health status [26]. However, parents consider communication to be effective when it appears to be responsive to their needs and evolves according to their current needs [23]. It is therefore recommended to adapt the discourse to the parents' level of understanding and medical knowledge [33]. The information provided should be repeated and personalized [29,33].

Doctors should ensure that the parents understand the information given and express their agreement or doubt [23,33]. Ideally, information should be given to both parents and, if possible, accompanied by written material [31]. To ensure that parents understand the reality of their situation, communication should be personalized taking into account sustainability, beliefs, possible disabilities, and values [27,29,34]. Parents prefer doctors to limit medical jargon in their exchanges and they want conversations to be realistic and truthful but tempered with hope [27]. When the amount of information is inadequate, parents may feel overwhelmed or feel that doctors are withholding information from them. In addition, too little or too much information hinders understanding, limits decision-making, and increases parental stress [33]. Conversely, favoring the same interlocutors, when a trusting relationship has been established, reduces parental stress and facilitates collaboration and decision-making [25,29].

#### *3.3.4 Inclusion of parents*

Ballantyne et al. found that parents experience increased stress, uncertainty, and fear when they do not feel included in NICUs [20]. Parents expressed increased feelings of powerlessness when they felt that professionals were not accessible [20]. Conversely, when their presence at visits and care is encouraged, parents feel that they have more control over the situation [20] because they can more easily discuss and ask questions of caregivers [26]. When parents are given special time with nurses to help them understand and participate in

care, their anxiety decreases and their need for reassurance about their parenting is reduced [20, 23, 34]. The belief that prior consent is required from caregivers to touch their child weakens the parent–nurse trust relationship [25]. Mothers may feel frustrated at not being able to care for their infants as they would like [25], while nurses express apprehension and fear for the child’s health [26,31].

In addition, communication is considered ineffective by parents when they feel they have difficulty asking for help or when caregivers are too prescriptive about instructions and care [25]. Conversely, communication is considered favorable and part of a trusting relationship when it creates a sense of partnership and equality between nurses and parents [26]. However, support should take into account the needs and feelings of both parents and not focus primarily on the mother, as recommended by the guidelines resulting from the family-centered care approach [10, 31].

### *3.3.5 Shared decision-making*

A majority of parents are satisfied when they are actively included in discussions and decisions about their child [33]. However, some parents report that a lack of communication with doctors makes it difficult to participate in decisions about their child [29]. This may be explained by the desire of professionals to protect parents from difficult decisions [29, 34]. However, for parents, making difficult decisions is also part of their role as parents. They regret not being fully informed of the situation by professionals [29]. Nevertheless, they express a need for support and compassion from caregivers to support them in their choices, even if they may rely on their spiritual or religious values when making decisions [29].

Depending on the situation, parents are involved at different levels in shared decision-making [27, 35]. In order to be involved in decision-making, parents need to understand the situation. They want to receive information about pain, the child’s suffering, the potential after-effects, the risks of death, and the financial aspects [27,29]. Shared decision-making is also linked to

parents' feeling of confidence in the skills and reliability of the information provided by health professionals [35].

For their part, doctors believe that their role is to guide parents toward an authentic and realistic decision [29]. To do this, they feel it is necessary to understand the family context, the way parents perceive their child's health status, and the quality of their knowledge about the disease trajectory [34]. Finally, doctors declare that they did not receive adequate training during their medical course in the communication skills necessary to be able to respond to parents' relational needs [34].

#### **4. Discussion**

In the NICU, communication between caregivers and parents is a prerequisite for shared decision-making and the medical care that depends on it [4, 12, 19]. The quality of the communication is seen as one of the most important conditions for creating a trusting interpersonal relationship and moving toward the ideal of "shared decision-making" [12, 19]. Information and communication are particular needs for parents in this type of environment because they are confronted with a situation of shock and stress and have to deal with fear and anticipation of the situation in a context of uncertainty [7, 8, 9]. Parents' emotions have an impact on their concentration, communication and interpersonal skills, and decision-making abilities [11, 19].

In NICUs, parents are confronted with exceptional situations in which their communication skills as well their ability to develop a trusting relationship are crucial. This specific environment therefore confronts caregivers and parents with significant communication and information challenges.

##### *4.1 Main results*



The results of this literature review show that the implementation and development of *family-centered care* practices (dignity and respect, information sharing, family involvement in care and collaboration) are able to meet the different relational needs of parents and address the associated stress and anxiety factors [17, 22–27, 29, 31, 34].

#### 4.1.1 *Family expectations*

This synthesis highlighted several expectations in terms of communication (**Table 2**). First of all, the data showed that parents need professionals to engaged in a supportive and empathic communication style with them that enables open and honest exchange [21-23, 27, 29, 30, 32, 34]. Parents also expect communication that allows them to fulfil their parenting role [25, 29, 30] and that they are provided with the information necessary to reduce their fear of uncertainty [21, 23–28, 32, 33]. In addition, the adaptability of caregivers' communication style to the context and changing parenting needs promotes the caregiver–family relationship [23]. Conversely, the relationship of trust is undermined when caregivers do not meet the parents' need of being included in the care and decision-making related to their child's health status [23, 25–27, 31, 33–35]. Therefore, meeting these communication expectations can limit families' doubts about the reliability of the information provided to them and also reduce parental stress and anxiety [35].

#### 4.1.2 *Tools for better communication*

This review also allowed us to take stock of the different mechanisms that can promote communication between caregivers and families in the NICU (**Table 3**). Prenatal consultations and/or early interviews during the child's admission are a response to the parents' needs for support and reassurance [25]. Indeed, several studies have shown a decrease in fear and uncertainty when parents were offered detailed explanations of how the NICU works [23–25]. Pretransition interviews with the child also facilitate the reduction of apprehension [25].

In the case of distance from the parents, teleconferences and SMS can help to communicate information about the child's health, while webcams can facilitate meeting with the whole family and allow for a more complete assessment of the family situation, thus offering caregivers the possibility to adapt their communication style to the context [21, 22, 28].

Finally, other studies have shown that palliatives programs consisting of interviews, funeral support, and support groups can reduce families' psychological distress and pathological grief [32].

#### 4.2 Limitations of the study

The articles selected for our review focused on the different communication needs of parents, their experiences, their satisfaction, and the means used to improve the relationship of trust between caregivers and families. The different reviews focused either on an analysis of communication tools and devices or on the evaluation of communication by parents. The studies identified did not focus on the specific content of the communication but on the analysis of the devices put in place and the assessment of the decision-making and communication experiences of parents and caregivers. Moreover, only one study focused on the specific perceptions of fathers.

In addition, the English language as a criterion in the article selection process may have limited access to information related to culture- or language-specific relational and communicational dynamics. Even though some of the reviews we selected had conducted ethnographic studies [30, 35], families' expectations and needs in terms of communication could not be linked to specificities in terms of culture, beliefs, or social level. The only review that chose the ethnic variable as a selection criterion [35] noted as a limitation the tendency of the majority of the participants to be represented by Caucasian people.

#### 4.3 Perspectives

This summary highlighted the presence of communication barriers, mainly due to the inappropriate use of a needs' analysis tool by professionals [23], or a feeling expressed by doctors that they lacked the communication skills needed during their training to be able to respond adequately to families' needs [34,36] (**Table 4**).

These observations corroborate the findings of Carter and Lantos [37] and call for the development of teaching and learning of communication and interpersonal skills for caregivers during their initial training but also as part of continuing education. The development of appropriate teaching related to professional, psychosocial, and ethical issues can contribute to the development of family-centered care. These training programs must be based on the literature and on field research [38], which sheds light on the processes influencing care practices at a communication and relational level in the context where care situations are full of particularly salient representational, psychosocial, and ethical issues. This new research can contribute to the development of new training tools adapted to communication (modalities, contents). In turn, these new innovative training tools can contribute in the short and long term to the improvement of professional and communication practices. Training in communication through simulation tools can offer caregivers an opportunity to analyze their experiences and allow them to reflect on the experiences through the contextualization of the exchange situation with the families and borrowing from their practice environment. The time spent in successive exchanges during the exercises inherent to this methodology is also an asset for the acquisition of relational skills, empathy, and adaptability to the specific situations of neonatology [4, 5, 6].

Several authors [22, 29, 32] have shown certain beneficial effects of the development of devices favoring social support (support groups, social networks) on stress, anxiety, and psychological distress of families. The establishment of "parent cafés" supervised by an NICU psychologist could be a response to parents' need for support and reassurance. These

discussion sessions would offer families a space to express their feelings and fears and to share experiences. Affective and emotional tensions could be reduced and a better relationship between caregivers and families may be established.

## **5. Conclusion**

This review shows that the family-centered care approach and the development of communication devices for parents are central to the concerns of NICUs. Numerous studies report on the communication and relationship needs of families, but few focus on the content and situational side of exchange. The development of new communication training systems seems essential for improving care practices in NICUs.

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**Table 1.** Summary of the design and topics of study in the included reviews

<b>Authors</b>	<b>Year</b>	<b>Study model</b>	<b>Selected references</b>	<b>Research subject</b>	<b>Discussion</b>
Anwar Siani et al. [21]	2017	Scoping review	10 references including 2 controlled and randomized trials, 2 qualitative studies, 2 observational studies, and 4 quantitative studies.	Integration of e-health outcomes of preterm infants in the NICU and at home.	Usability and feasibility of e-health and perceived benefits; use of knowledge.
Arzuaga et al. [34]	2019	Traditional review	22 references of studies or articles.	Medical decision-making, data communication and practices surrounding extremely preterm birth.	Organization, content and protocol of the “counseling” interviews.
Ballantyne et al. [20]	2017	Scoping review	11 references of studies.	Experiences and needs of parents of premature and critically ill infants such as their transition from postpartum care.	Parents’ distress; change in parenting role; source of stress; perceived support.
Brødsgaard et al. [26]	2019	Qualitative systematic review and meta-synthesis	21 references including 20 articles and 1 thesis	Parent–nurse relationship in NICUs; barriers and existing facilitators to a successful partnership.	Co-creation of knowledge; development of skills and negotiation of roles.
deHoff et al. [22]	2016	Scoping review	Not indicated	Information needs, barriers to education and face-to-face communication and the effectiveness of electronic media for health education: e-health challenges among parents of children with special health care needs.	Communication by mobile phone, use of mobile phone and applications; information collected through social networks.

**Table 1. (continued)** Summary of the design and topics of study in the included reviews

<b>Authors</b>	<b>Year</b>	<b>Study model</b>	<b>Selected references</b>	<b>Research subject</b>	<b>Discussed subjects</b>
De Rouck et al. [23]	2009	Traditional review	78 references including 53 observational studies, 4 controlled and randomized trials, 1 quasi-experimental study, 4 uncontrolled experiments, 4 interventions, 1 proposed intervention, and 11 reviews.	Information and communication needs of parents of children admitted to the NICU and their use of information sources in the trajectories in the NICU.	Information and communication needs; sources of information; trajectory: evolution of information needs; timing of information provision; communication style.
Ekberg et al. [33]	2018	Qualitative systematic review and meta-synthesis	29 references of descriptive or interpretative qualitative studies.	Communication experiences of healthcare users with healthcare professionals about children with life-limiting illnesses.	Communication experience: information, emotion, collaboration and relationship.
Epstein et al. [28]	2017	Systematic integrative review	11 references including 5 quantitative studies, 2 qualitative studies and 4 mixed studies; 8 of these studies were intervention tests.	Analysis of the use of technology in the NICU to facilitate communication and interaction.	Parents' perceptions of the use of technology for communication and interaction; perceptions of nurses of the use of technology for communication and its effects on workflow; outcomes for parents and infants associated with the use of technology in a NICU.
Goggin [29]	2012	Traditional review	Not indicated	Not indicated	Withdrawal from care and end-of-life decision-making; parents' perceptions (wishes, participation and practices).

**Table 1. (continued)** Summary of the design and topics of study in the included reviews

<b>Authors</b>	<b>Year</b>	<b>Study model</b>	<b>Selected references</b>	<b>Research subject</b>	<b>Discussed subjects</b>
Govindaswamy et al. [24]	2019	Systematic integrative review	20 references including 18 using a quantitative method and 2 using a mixed method.	Current needs and stressors of parents of infants hospitalized in an NICU.	Needs of families; stressors of parents of preterm infants in an NICU.
Harvey et al. [32]	2008	Systematic integrative review	21 references including 1 controlled and randomized trial, 4 cohort studies with nonrandomized controls, 1 cohort study with historical controls, 1 longitudinal study, and 15 qualitative or descriptive studies.	Effectiveness of bereavement interventions or offers of support for parents at and after the death of a baby in a NICU.	Bereavement support groups or counseling; providing information on parental bereavement; neonatal palliative care program.
Kharrat et al. [27]	2018	Systematic qualitative and discursive review	19 references selected including 16 using an interview method and 3 using a questionnaire method.	Prenatal and prematurity consultations: context, time, types of professional, information discussed, resources and aids, communication.	Framework for prenatal consultation for extremely preterm infants; desired time for consultation; type of professionals; information discussed; resources or aids; manner and style of communication.

**Table 1. (continued)** Summary of the design and topics of study in the included reviews

<b>Authors</b>	<b>Year</b>	<b>Study model</b>	<b>Selected references</b>	<b>Research subject</b>	<b>Discussed subjects</b>
Pladys et al. [31]	2019	Systematic review and position paper	169 references including 82 prospective studies, 35 retrospective studies, 52 reviews (systematic, meta-analyses, reference documents, recommendations).	Going from hospital to home: risk of depression, posttraumatic stress in mothers and families, and risk of re-hospitalization of premature newborns.	How to assess and support parenting skills; how to assess the abilities of the newborn; professional skills to be mobilized after discharge from conventional hospitalization; limiting re-hospitalizations; impact of early intervention programs in hospitals on the discharge method; specific situations to be taken into account; information and mode of communication.
Reid et al. [2019]	2019	Integrative systematic review and meta-analysis	31 references selected.	Identifying the perceptions of mothers and fathers of newborns admitted to NICUs regarding the role of neonatal nurses in the provision of family-centered care and the ability of neonatal nurses to interpret and respond to the needs of parents.	Process of becoming a parent; infant safety; barriers to parenthood; nursing support given to parents; communication; parenting inhibited by neonatal nurses.
Rosenthal et al. [35]	2013	Systematic review and meta-ethnography	10 references of qualitative articles.	Parental involvement in ethical decision-making for critically ill newborns.	Involvement of parents in decision-making; parenting role; need for good information; need for communication; satisfaction with decision-making; confidence in the healthcare team.

**Table 1. (continued)** Summary of the design and topics of study in the included reviews

<b>Authors</b>	<b>Year</b>	<b>Study model</b>	<b>Selected references</b>	<b>Research subject</b>	<b>Discussed subjects</b>
Sisson et al. [30]	2015	Qualitative systematic review and meta-ethnography	24 references from studies conducted in 12 different countries.	Fathers' experiences in the NICU environment.	Proximity; parental autonomy; vulnerability; communication; exclusion; isolation.

NICU: neonatal intensive care unit

**Table 2.** Summary of parents' specific experiences and expectations related to communication and information sharing in the NICU

Components of communication	Positive experiences and associated expectations
Communication style	<ul style="list-style-type: none"> <li>- Empathetic and supportive communication</li> <li>- Open and honest exchanges</li> </ul>
Communication time	<ul style="list-style-type: none"> <li>- Providing time and space for parents' thoughts</li> <li>- Multiple opportunities for discussion with professionals</li> </ul>
Communication mode	<ul style="list-style-type: none"> <li>- Communication that responds to parent demand</li> <li>- Professionals aware of changes in parents' needs</li> </ul>
Parental inclusion	<ul style="list-style-type: none"> <li>- Inclusion in care</li> <li>- Attendance at clinical rounds</li> <li>- Consideration of both parents</li> </ul>
Sharing decision-making	<ul style="list-style-type: none"> <li>- Participation encouraged</li> <li>- Consideration of values and beliefs</li> <li>- Responding to their need for information</li> <li>- Support and reassurance about their choice</li> </ul>

NICU: neonatal intensive care unit

**Table 3.** Summary of the devices studied for improving communication

Devices studied to facilitate communication	Associated needs of parents
<ul style="list-style-type: none"> <li>- Use of new communication tools: videoconference, webcam, SMS</li> </ul>	<ul style="list-style-type: none"> <li>- Need for reassurance</li> <li>- Need for legitimacy</li> <li>- Need for support</li> <li>- Need to understand and prepare</li> <li>- Need for security</li> </ul>
<ul style="list-style-type: none"> <li>- Development of palliative or end-of-life support programs: interview, discussion group, funeral support, etc.</li> </ul>	<ul style="list-style-type: none"> <li>- Need for support</li> <li>- Need to understand and prepare</li> <li>- Need for legitimacy</li> <li>- Need for time</li> </ul>
<ul style="list-style-type: none"> <li>- Setting up of prenatal obstetric-pediatric interviews.</li> <li>- Early admission interview</li> <li>- Transition preparation interview</li> </ul>	<ul style="list-style-type: none"> <li>- Need to understand and prepare</li> <li>- Need for time</li> <li>- Need for reassurance</li> <li>- Need for legitimacy</li> <li>- Need for security</li> </ul>

**Table 4.** Barriers to and influences on communication between caregivers and family in the NICU

Barriers to	Influences on
<ul style="list-style-type: none"> <li>- Exclusion of fathers from the care partnership</li> <li>- Multiple caregivers</li> <li>- Lack of perception of changes in and uniqueness of parents' needs</li> <li>- Technicality-complexity of language</li> <li>- Temporal brutality (information too fast, discrepancy of temporality with the doctor)</li> <li>- Poor consideration of the context</li> <li>- Tendency to protect parents from difficult decisions</li> <li>- Desired level of involvement of parents poorly identified</li> <li>- Feeling of parental inferiority, inconvenience, unease</li> </ul>	<ul style="list-style-type: none"> <li>- Communication style: support and empathy; open and honest exchanges; clarity of language</li> <li>- Temporality: multiple discussion times with professionals; offering parents time to think together</li> <li>- Inclusion of parents: inclusion in care; presence of parents at clinical rounds; consideration of both parents</li> <li>- Favoring participation of parents favored in decision-making</li> <li>- Anticipation and identification of parental needs: prenatal consultations, preparation for the transition of care</li> </ul>

NICU: neonatal intensive care unit.

**Figure:**

**Figure 1:** PRISMA diagram of the process of identifying and selecting articles for inclusion in the review.



**Figure 1:**

